Mother Writes: Writing as Therapy for Mothers of Children With Special Needs

by

Harriet Greenstone

McGill University
Montreal, Quebec

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements of the degree of

Doctor of Philosophy
in
Integrated Studies in Education

February 2006

Your file Votre référence
ISBN: 978-0-494-25159-1
Our file Notre référence
ISBN: 978-0-494-25159-1

Abstract

This study integrates the research on the social construction of motherhood as it applies to mothers of children with special needs. More specifically, it looks at how writings by these mothers can (a) help them cope with the emotional ramifications of having such a child, (b) contribute to the knowledge base of professionals who deal with and nurture not only children with special needs but also their mothers, and (c) constitute an effective qualitative research tool.

The study focuses on the relationship between writing processes and products and the development of mothers' emotional states and emotional development, their self-image, self-confidence, role identity, and comfort. It investigates feelings of inadequacy, guilt, anger, and frustration, especially those engendered by good mother/bad mother social judgments, to which mothers of children with special needs are particularly vulnerable.

I came to this area of research organically – as a clinician, as a teacher, and as a mother of a child with special needs myself. Van Manen (1990) suggests there is no better way to understand a phenomenon than to live it. I realized I was uniquely positioned to understand, examine, and synthesize the therapeutic effects of mothers' writing, reading, and storytelling, and understand the social environment that fuels it. As a clinician and educator, I also recognized its value as a rich, yet relatively unexplored, source of knowledge.

In preparation for designing the study, I looked beyond peer-reviewed literature to popular literature, including diaries and autobiographies of mothers, to familiarize myself with their writings and the impact of such writings on the mothers' emotional

adjustments, including their need for expression, support, and advocacy – for themselves and others.

The study describes the experiences of a writing group (eight participants) comprised of mothers of children with special needs. The group met weekly for ten weeks to examine and share their feelings and life stories through a series of written assignments. Common themes and individual responses to this experience were captured anecdotally throughout the sessions, as well as in pre- and post-group interviews.

Following a description of how the study evolved, coinciding with my personal shift from quantitative to qualitative researcher, I begin with a comprehensive review of mothering as a research area in literature, and a review of literature on the therapeutic effects of reading, writing and storytelling. I then discuss the methodology of this study with an emphasis on the literature on focus groups, memory work, narratives and writing, as well as qualitative research tools and techniques. The results of the study are presented descriptively using primarily a narrative approach, including a more detailed analysis of the experiences of four mothers who participated in the study.

All the mothers reported beneficial effects from their participation. They felt empowered by the experience and inspired to continue to use writing, not only for its individual therapeutic effect but also as a means to advocate and inform others. The connection between writing and advocacy was a recurrent theme that emerged from the study – a strong common desire to help others, and the recognition that writing was an effective means to accomplish the mothers' goal to have professionals understand them better, individually and as a whole, and to be more empathetic.

Other findings include the incongruence of thought between mothers and professionals, and the need to deepen our understanding of parent-professional interaction; and how much more impact the mothering debate has on mothers of children with special needs, particularly the stay-at-home versus working mothers' argument.

This study provides insight into the extensive thoughts and emotions experienced by these mothers, and furthers our understanding of themes like stages of mourning for the not-so-perfect child, and the inter-related processes of storytelling, reading, and writing. It also has implications in the field of memory work, looking at how these mothers recalled early events in the lives of their children and how they remembered their experience in the study, months after its conclusion. Finally, it discusses the implications of using therapeutic writing as a qualitative research tool.

The study concludes with suggestions for using writing to facilitate communication and understanding between parents and educators as well as between parents and other professionals, for their mutual benefit.

Résumé

Cette étude combine une recherche sur l'édification sociale de la maternité telle qu'elle s'applique aux mères d'enfants à besoins spéciaux. De façon plus précise, nous allons voir comment les écrits de ces mères peuvent (a) les aider à affronter les ramifications émotionnelles vécues en ayant un tel enfant, (b) contribuer à la banque de connaissances des professionnels qui s'occupent et éduquent non seulement les enfants à besoins spéciaux mais également leurs mères et (c) constituer un outil de recherche qualitatif et efficace.

La relation entre le processus d'écriture, ainsi que ses dérivés, et le développement des états émotionnels de la mère, son développement émotionnel, sa propre image, sa confiance en soi, son identité et son confort constitue le centre d'intérêt de cette étude. On y examinera les sentiments d'inaptitude, de culpabilité, de colère et de frustration, plus spécifiquement ceux engendrés dans le contexte de bonne maman/mauvaise maman auxquels les mères d'enfants à besoins spéciaux sont particulièrement vulnérables.

Je suis parvenue dans ce domaine de la recherche organiquement, en temps que clinicienne, professeur et moi-même mère d'un enfant à besoins spéciaux. Van Manen (1990) sous-entend qu'il n'y a pas de meilleure façon de comprendre un phénomène qu'en le vivant soi-même. J'ai compris que j'occupais une position unique pour comprendre, examiner et faire la synthèse des effets thérapeutiques des écrits, lectures de ces mères et des histoires racontées par elles, tout en comprenant l'environnement social qui les nourrit. À titre de clinicienne et éducatrice, j'ai également pu reconnaître la riche valeur, relativement inexplorée, de cette source de connaissance.

Lors de la préparation de cette étude, j'ai regardé outre la littérature professionnelle. J'ai étudié la littérature populaire, incluant les journaux intimes et autobiographies de mères afin de me familiariser avec leurs écrits et l'impact de tels écrits sur l'ajustement émotionnel des mères, incluant leur besoin d'expression, support et plaidoyer pour elles-mêmes et les autres.

Cette étude décrit les expériences d'un groupe d'écriture de 8 participants composé de mères avec des enfants à besoins spéciaux. Ce groupe s'est rencontré hebdomadairement pendant dix semaines pour examiner et partager leurs sentiments et histoires de vie à travers une série de dissertations écrites. Les thèmes communs et réponses individuelles à cette expérience ont fait l'objet d'anecdotes captées tout au long des sessions de même qu'au moment des pré- et post-entrevues de groupe.

Suite à la description de l'évolution de l'étude, coïncidant avec mon changement personnel de chercheur quantitatif à chercheur qualitatif, je commence une revue compréhensive des soins maternels comme domaine de recherche dans la littérature ainsi qu'une revue de la littérature des effets thérapeutiques de la lecture, l'écriture et les histoires racontées. J'ai après discuté de la méthodologie de l'étude avec une emphase de la littérature sur les groupes concentrés, le travail de mémoire, les narrations et les écrits de même que les outils de recherches qualitatifs et les techniques. Les résultats de cette étude sont présentés de façon descriptive en utilisant principalement une approche narratrice tout en incluant une analyse plus détaillée des expériences de quatre mères ayant participé à l'étude.

Toutes les mères ont déclaré avoir bénéficié de leur participation à cette étude. Elles se sont senties plus fortes grâce à celle-ci et inspirées pour continuer à écrire, non

seulement à des fins thérapeutiques individuelles mais aussi à titre de plaidoirie et pour informer les autres. La relation entre l'écriture et la plaidoirie était un thème récurrent qui émergeait de l'étude - un fort désir commun d'aider les autres, et la reconnaissance que l'écriture était un moyen efficace d'accomplir le but des mères vers une meilleure compréhension de la part des professionnels, individuellement et en groupe, et permet à ceux-ci de démontrer plus d'empathie.

D'autres conclusions incluent l'incongruité entre les pensées des mères et des professionnels de même que le besoin d'approfondir notre compréhension de l'interaction parent-professionnel. Toujours parmi les conclusions, on retrouve combien d'impact le débat sur les soins maternels a sur les mères d'enfants à besoins spéciaux, particulièrement l'argument mère à la maison versus mère travaillant à l'extérieur.

Cette étude nous permet de comprendre les fréquentes pensées et émotions ressenties par ces mères et approfondit notre compréhension de sujets tel que les stades du deuil de l'enfant pas-parfait et le processus inter-relié d'écriture, lecture et histoire racontée. Il y a aussi des implications dans le domaine du travail de mémoire, en regardant comment ces mères se souviennent d'événements survenus tôt dans la vie de leurs enfants et comment elles se souviennent de leur expérience durant l'étude, des mois après sa conclusion. Finalement, une discussion sur les implications de l'utilisation de l'étude thérapeutique comme outil de recherche qualitatif a lieu.

Les conclusions de l'étude suggèrent l'utilisation de l'écriture pour faciliter la communication et la compréhension entre parents et éducateurs de même qu'entre parents et autres professionnels pour leur bénéfice mutuel.

Acknowledgments

To complete a thesis from just a seedling of an idea and make it blossom into a document of this magnitude has been challenging at the very least. I could never have accomplished such an incredible feat without the invaluable support of my fellow colleagues, peers, co-workers, and wonderful family.

It is with tremendous gratitude that I thank Dr. Claudia Mitchell for having been there for me right from the beginning – encouraging me, helping me, guiding me and inspiring me. Claudia, you are an exceptional person and a gifted advisor. It has been a pleasure working with you and learning from you. I am truly indebted to you for probing my ideas and inspiring me to delve even further. I have also been extremely fortunate to have such capable, intelligent Ph.D. thesis committee members who shared their own ideas, unique personalities, and expertise in their respective fields. I thank you all for your assistance, encouragement and your wonderful ideas. Dr. Linda Davies, I learned so much from you about Feminism and about mothering. Your input has always been most appreciated and respected. Dr. Ann Beer, I am grateful to have had the opportunity to learn from you about autobiographical writing. I enjoyed our wonderful meetings when we talked about writing, autobiography, mothering, "special" mothering, and so much more. I thank Dr. David Dillon for his helpful comments and advice.

Joan Scott – you are a friend beyond words. Even before the idea for my thesis was planted, you have been there for me! I could not have achieved this without our innumerable midnight talks until two in the morning, where we exchanged and dissected ideas.

To the people in my office, Alida, Elaine, Alana, and Tamara, although my thesis did not fall under your portfolios, you graciously assisted me by pinch hitting with the technical stuff and sharing me with McGill. I am very grateful and thank you for all of your help.

To all the mothers who participated in the study, I owe my sincere gratitude and appreciation. Of course, without you this project could never have been realized. You shared your time, your thoughts, and your inner emotions with me. You trusted me and I counted on you. You were my research partners in the truest sense of the words. I can never thank you in the way that you all deserve, but I do promise that I will try to have your words and your messages read and heard.

To my mother Frances Isenberg, who, by your own example, has shown me the true meaning of being a mother and nurturer. You have supported me in my endeavors – including my academic aspirations - from the time I was young right up to the completion of this thesis. In so many ways you are there as my coach and my cheerleader. I love you and admire you. There are no words to express my gratitude.

To my husband, Warren, thank you firstly for enabling me to be a mother! Initially, in the 70s and 80s, you resembled more of a father of the 50's. You were a fine example of the fathers that I write about in my research. Somewhere down the road we became partners in every sense of the word, including in our roles as co-parents. In the last months, your support has been invaluable in helping me to get this thesis to the finish line. Whether running to Bureau en Gros in the middle of the night, picking up documents for me, or helping me with anything else that I needed, you were always there to lean on. I love you more and more each day. Thank you.

To my mother-in-law, Andoretta Greenstone, thank you for sharing your son with me.

Finally, to my children Mara Rebecca, Randy Rachel, Meryl Carla, Hilary Paula, and Shawn Casey, of course you are what makes me a mother! Shawn, the girls have been through the thesis experience before (with my Masters). This was your first time. Good job, and thank you!

Besides providing me with the experiences which served as the foundation for much of my learning and research, each and every one of you children is so special in so many ways. You have encouraged me and shown pride in my studies and have made me proud in turn, to see your pursuits of your own individual goals and careers. You all supported my work and patiently allowed me the time and space to complete my research.

It is to you, my loves, that I dedicate this thesis.

Table of Contents

Prologue

I have always used writing as a method of self-expression-in the many "unsent letters" I penned to relieve my anger and frustrations, as well as in the poems I wrote to show my love or appreciation or to describe my emotions. It was through the act of putting pen to paper that I was able to liberate my inner self and reveal some deep-set feelings.

One of my most cherished writings is a poem I wrote many years ago about my "special" child and my "not-so-special" community.

Not so very long ago
Our sweet baby was placed in our arms
And very very quickly
We all saw her beauty and charms

Very soon after from our joy
Came some pain
When we found out that our precious
Had a not so perfect brain.

Of course the Doctor's words
Raised many many fears
And our worries and shattered dreams
Produced many, many tears.

We always found strength,
From her beauty and her charm
And from her incredibly warm heart
One who could do no harm.

The most outstanding part
Our little girl's best trait
Is that she believed that everyone
She meets is truly great.

She possesses a love for everyone
An unrelentless love
And an equality for everyone
No one being below or above.

To watch all her gentleness
The way for others she does care
For sure makes her special
In a way that is rare.

When my father walks in the house
Holding on to his cane
She runs to help him
As for her helping is no strain.

Why, I ask if she
Can help and think of all and one
Why then do other people
Talk, laugh or make fun.

So our little girl
May learn a little more slow
There are parts that she possesses
That many "normals" will never know.

I have been appalled and amazed
When she's refused to a camp or school
Because my little girl's development
Doesn't follow every rule.

I wonder and wonder who
It is in fact
Who possesses the most
Major of all handicaps.

Is it my little girl
Who goes a little slow
Or is it those who are ignorant
Of those who the "normal" path don't go?

We no longer suffer much from
The knowledge of her so called imperfect brain
But our community's ignorance is
Our true source of pain.

For IQ is only a part of
The complexity of mankind
And some so called handicapped
Possess beauty that in other's you'll never find.

I pray to God each day
That my baby's inner beauty will never change
And I pray to God that those who are ignorant
Will learn of the human range.

I pray to God that we can learn
To accept the ignorance we confront each day
And that our community will learn
To accept each individual for their own way.

To this day when I read the poem, I am able to relive those old emotions, and rediscover new ones. It stirs memories of the "me" before the diagnosis that changed my family's life and the "me" after. The poem helps me recall details of those precious early days, the little details we think we'll always remember but inevitably fade if not recorded. It stirs compassion for the "naïve me" who was astounded that so many could treat my daughter so unfairly. And as I relive the fears and dreams I had for her future, I am struck by how far we've come. I'm grateful that my daughter's generous spirit and enormous heart have endured, even blossomed. And I'm proud of my small part in that. I remember the battles we fought and won, and those we lost. They made me stronger. I realize how much I've learned from her, that I'm a better parent, a better psychologist, a better person, because of her. It's almost as if the "me then" and the "me now" are reaching out to counsel and support each other across time.

Little did I know, when I penned those first lines, that it was the beginning of not just a personal journey but also a professional journey. A journey that has led me here, to a study of the value of therapeutic writing in qualitative research. A journey that I hope will help others as much as it's helped me.

Chapter 1: Introduction

"How can I know what I think till I see what I say?"

When I first read this quote by novelist E. M. Forster, I immediately understood its relevance with regards to writing as therapy. In this introduction I discuss how this concept, coupled with life events (personal and professional) was the fertile ground in which the idea for this study first took root – a study of the therapeutic effects of writing, particularly by mothers of children with special needs, and the use of such writing as a qualitative research tool.

As Van Manen (1990) suggests, our life experiences help to situate us and formulate our research interests and ideas. I am a research psychologist and the director of a multidisciplinary centre for children with developmental, learning, emotional and psychological disorders, and their families. I recently began teaching child development courses at the college level to Early Childhood Education students. These experiences allow me to view parenting children with special needs from a number of perspectives – parent, teacher, and psychologist.

In my role as psychologist, I have drawn on my own positive experiences with the therapeutic effects of writing, extending this experience to my clients as a therapeutic tool. I began to conduct groups, some specifically geared toward mothers, using writing and bibliotherapy as a means by which group participants could tap into their conflicted feelings or frustrations, and come to a level of self-understanding and calm.

Many of these women reported that several of the books chosen for reading helped them to better understand and deal with their own problems, as well as with the unique problems of their children. One mother handed me a summary of her child's

school history and said, "This is amazing. As I condensed everything down to its barest bones, this pattern just popped out at me. It makes a lot of sense, but I'd never recognized it!" In other instances, when I would ask adolescents or adults to write journal entries to be used as discussion points at our next session, I was struck by how the process of writing increased their level of clarity and insight into their situations in a way that they were unable to achieve verbally. I also asked mothers to keep a log of their child's behaviours, an exercise they said helped them not only to identify trends in their child's behaviours, but almost more importantly, it helped them reduce their anger and frustration. They reported that escaping to a quiet place and writing it all out helped to calm them down, while later reading it back often put things into perspective and also helped to gain a better picture of the situation.

I soon realized that entwined in the reading and writing process was the act of storytelling. Reading what other mothers had written initiated conversations that led to the telling of more stories. The act of re-telling of their own story resulted in many of my participants, as well as myself, expressing heightened emotions when reading words we had previously written. These emotions were often described as more intense than those felt in the initial writing process. There seemed to be an interchange between reading, writing and storytelling that resulted in the teller or writer of the stories benefiting in some way.

I became more and more excited about the benefits of reading and writing, and began to focus on using writing therapeutically and as a qualitative research tool. As I read the literature on qualitative research, I became more interested in looking at not only

the writing of others but my own writing too, and my thinking before, during and after writing. I turned to researchers such as Max Van Manen.

I first thought Van Manen's work (1990) was in dramatic contrast with my own initial research orientation which relied on very strict quantitative analysis and experimental method. Terms such as "manipulating the variables", "cause-effect", "extraneous variables", "subject", and "measurement" were a very big part of my vocabulary. As I re-read the method section for my final drafts of this thesis, I realized how far removed I have become from a quantitative research orientation.

My first years in the field of psychology were at a time when the discipline was working very hard to be identified and respected as a science and not an art, which meant that human behaviour was taken into the laboratory to be dissected and studied very carefully. Although this did give us some very valuable information, it certainly had its limitations. From there, I spent a brief period of time studying and considering epidemiological research. I thought of using extremely large sample sizes and very discreet quantitative variables to look at such issues as the possible causes of disorders such as Autism, and statistics that examined the increase or incidence of these disorders in different parts of the world, the relation to vaccinations, to food and so on. Although this was very interesting, and has definite merit in epidemiological type studies (i.e. incidence, prevalence etc.), it had no direct implications in psychiatry, psychology, education and the human part of medicine – where I felt a qualitative approach would be more useful.

I kept thinking of ways I could show how this could be an effective method and looking to the literature for validation. I now understand how this search for validation

was at least in part related to an issue of trust. Ely, Anzul, Friedman, Garner, and McCormack Steinmetz (1991) explain this need to be convinced as a need to trust. Ely states that:

> Learning to trust the process of qualitative research is difficult for many students of the field, particularly at the beginning. It is of course essential if one wishes to be a qualitative researcher. In my experience, this learning is highlighted as students work in two arenas: learning to trust the research paradigm itself, to accept that it is worthy and respectable, and learning to trust oneself as a flexible instrument. (p. 32)

I believe I was working through both these issues, trusting myself and trusting the process. I needed to feel confident in this type of research as well as in my ability to bring this research method to its fullest potential. As I worked through this, I found the message in the professional world to be inconsistent, confusing and often contradictory. I reflected upon how doctors and psychologists use the case study approach with each client/patient. They begin with an interview, collecting their data from historical information. The patient, or in the case of children, the parent(s) are asked many questions, in an interview format, to obtain a medical history (i.e. to get "the story"). Sometimes they give out questionnaires and they usually ask for supporting documents. They then observe the patient/client and make anecdotal notes. They study any supporting documents, lab reports, psychological testing, notes or reports from other doctors. They may then examine the patient/client, recording more notes and finally put the information together and compare it to what they've learned, read or seen in other patients/clients. How, I asked myself, does this differ from a qualitative case approach? Students in these fields

are trained in the art and science of gathering information, and in studying available data. They are taught the importance of studying all the data while researching the case. Often an astute clinician will formulate a hypothesis based on noted similarities and then do a comparative case study to further investigate their hypotheses.

Often text books and journal articles, dealing with specific syndromes and treatments, use vignettes of true case examples to illustrate their points. Yet I keep feeling frustrated when I attend conferences, where the speakers refer to case studies and individual examples over and over again, while quickly adding comments such as "those were anecdotal notes only" or "of course this has not yet been substantiated by real scientific research."

I once attended a conference on chronic illnesses and disabilities in children. I was very impressed by the keynote speaker's observations that when treating children requiring chronic care, the parents must be part of the team. He went on to say that the parents, often the mothers, become the experts not only of their child, but of the disease or disability their child is suffering from. He alluded to research that he had done, where he interviewed parents of chronically ill children. Then he quickly moved on to something else. At the coffee break, I excitedly approached him to talk about this qualitative research. He responded, "Oh yeah, that was a long time ago, you can find it somewhere under my name." His response to my inquiries and his quick dismissal of his previous work and to my interest in this work, were strong indicators that the kind of descriptive research I believe is so important to our understanding of parents' feelings and needs when their children are suffering from chronic illnesses and disabilities, is still highly undervalued by many professionals in the health field. It was disappointing to

realize that a professional who so strongly stated how parents are the "experts" of their children's illnesses could so easily dismiss the importance of their responses to interview questions as a tool to understanding the phenomenon.

As I was preparing the final proposal for this thesis, I (in my "mother hat," not as a clinician) received a questionnaire developed by the nursing staff at a children's hospital in an attempt to evaluate the needs of families with children diagnosed with handicaps and/or chronic medical illness. Finally, I thought, they're listening to the parents! Then I read it. The structure was rigid. Parents were expected to choose from a pre-set list of responses to a pre-set list of what someone else considered important factors. Did I find my child's treatments "minimal" or "overwhelming?" There was no "it depends on the day, the treatment, my child's mood, the doctor's bedside manner, and what happened at the last treatment..." checkbox. Such a questionnaire might have garnered out-of-context snapshots of isolated elements that mattered to the hospital, but it didn't capture even a glimpse of the reality of families of children with special needs. This is where a working format similar to a focus group may be more beneficial. This is where listening to oral stories and reading the written stories of these families would be so much more enriching and informative.

Situations like this pushed me to move forward in the process, rather than to become discouraged. They made my mission clearer. I became more motivated to study the use of storytelling and writing to capture information that would otherwise be lost in the process of doing "pure" quantitative research. I realized a type of research was needed that really listens to the ongoing needs and concerns of the participants in a rich, comprehensive manner. I had finally learned to trust.

Autobiography of the Question

The frustrations I was feeling as a researcher, as a mother, particularly a mother of a child with special needs, and as a psychologist in clinical practice, had led me to look for a better way to communicate and address the complexities of human perceptions and emotions. They were the "autobiography of the question," as Jane Miller (1996) called it. So far, I had considered my own experiences as a clinician and mother, as well as the experiences of other mothers of children with special needs by listening to their stories and reading their autobiographies.

In my own experiences, I had dealt with a multitude of emotions with regards to the various "hats" I wore as a woman: that of a mother, a mother with a child with special needs, a wife, a daughter, a professional, and a researcher. Nowhere were my feelings as complex and emotionally charged as in my role as a mother, both to my "typical" children and to my child with special needs. It was imperative for me to learn more about these feelings before constructing my study. During this process I became more reflective, I began telling my own story more and I even began writing more about my personal memories, reflections, experiences and frustrations. I hesitated to do this at first for two reasons-it was inconsistent with my clinical and research training prior to this degree, and it wasn't only my story to tell. However, with encouragement from my dissertation committee, and with encouragement from the literature, I began the process and quickly realized why, as Van Manen suggested, there is no other way to understand a phenomenon than to live it – and to write it. My mind is the only mind that I can ever enter and truly read with accuracy. I say this with a little regret as I believe I'm a pretty good mind reader as a mother and as a clinician.

To understand the experiences of others, I began talking to other mothers and listening. I did this first informally with friends, then at work as well. I started keeping track of anecdotes and field notes. I began to realize even more clearly, how mothers are constantly using reading, writing, and storytelling to help themselves and their children. Whether they're writing letters to their children's teachers or magazine and newsletter articles, writing down their questions and concerns before a doctor's visit, or sharing their stories with other mothers in online chat rooms, mothers of children with special needs, in particular, seem to be driven to relate their stories in order to help themselves, their families, and others.

I also read published autobiographies written by mothers of children with special needs-the well established genre of published "mother-stories." I've always enjoyed reading for pleasure and found many of these to be well written, easily capturing and quick to hold my attention. As a mother of a child with special needs, I found these stories supportive, comforting and inspiring. Although at times, they did leave me wondering if I, as a mother, was doing enough for my children. Mostly, they helped me to see that my thoughts, fears and emotions were "normal" (i.e., felt by many others and that I was faring quite well). I also read them as a clinician, where I learned more than I had in many classes and in reading many textbooks and/or journal articles. I gained insights into the way parents perceive the different professionals, their actions and their words and I learned about many less known and/or alternative approaches that I had previously minimized. Interestingly, as I reflected on how this writing differed from professional literature, I realized that I most benefited from the brief vignettes used as illustrations in many texts and articles. Finally, I read these autobiographical accounts as

a researcher, gaining information through their stories and stimulating new ideas of my own. This latter use of autobiographies was new to me, I had to smile when I said aloud "I'm working on my thesis" while deep inside I hid how much I was enjoying this. More and more, the incredible value of the narrative as a research tool became more apparent to me.

I realized there are multiple ways of reading: for learning, for support, for enjoyment and as a valuable research method. Prior to beginning my project and right through to the present, I've been reading as many autobiographies, memoirs, or diaries of mothers of children with special needs as I could find. I broadened this to include writings by almost any writer about themselves and/or about their loved ones. When it was time to stop my literature review, I kept reading. I continued to find many of the same themes and emotions - mother guilt, good mother-bad mother, fear, elation, anger and ambivalence etc. - gleaming through the pages of each and every book I read.

These experiences – self-reflection, listening to other mothers, reading their stories – helped crystallize the questions I wanted to address in this study. How do mothers react to, adjust to, and feel about having a child with special needs? Do these mothers go through stages of feeling, reacting and adjusting, like the stages of mourning identified by Elizabeth Kubler-Ross (1997)? How do mothers feel about their relationships with others and the frequent, judgmental comments of others, particularly family, friends, health professionals and educators? What messages do they want these significant others to receive? Does writing help mothers of children with special needs to deal better with their emotions? Does writing help mothers of children with special needs to better organize their thoughts and problem solve? And ultimately, how can mothers'

writings be used as research data to better understand the phenomena and to develop health and educational services for children with special needs and their mothers?

In the Mothers' Words: Popular Literature on Mothers of Children with Special Needs

While I will focus on the peer reviewed literature in chapters two and three, in this Introduction I focus on the vast body of more popular literature written by mothers of children with special needs. For years, I had already been reading these types of accounts. There are many books on mothering children with special needs in both the professional and popular literature, many autobiographies discussing mothers' emotions, frustrations, battles, and triumphs, their courage, their discoveries and their stories (Beck, 1999; Colin, 1997; Foli, 2002; Ford, 2003; Fowler, 1993; Kephart, 1998; Shapiro Kramer, 1996; Maurice, 1994; Seroussi, 2000; Shilts, 1999). A browse through the Education, Psychology, Parenting, and Self-Help sections of any Chapters bookstore reveals dozens of such books. These books serve many purposes: from inspiring others going through the same or similar situations, to sharing ideas on treatment, strategies and methods that may work, to advocating for certain rights and beliefs. Although the stories deal with children of different ages, who have a variety of disabilities, there are common and recurrent themes running through these books that the readers are able to relate to. Feelings of love, fear, anger, ambivalence and frustration are dealt with, as well as themes familiar to the scientific literature such as mother-blaming and good mother/ bad mother.

Here I include a short discussion of the many journals, diaries and autobiographies written by mothers of children with special needs as a way to highlight

the genre itself and types of issues being addressed. *In Love As A Start...The Real Challenges of Raising Children With Emotional Disorders,* Shilts, (1999), an Occupational Therapist who adopted two children from her boyfriend's family tells her story. She describes in detail, the frequent frustrations, self-doubt and questions she had about whether she was a "good mother", the need for nurturing of herself and the need for validation of what she was doing. She nicely introduced the topic of Fetal Alcohol Effects (FAE). Buxton (2004) also wrote about her experiences as the adoptive mother of a child with FAE or Fetal Alcohol Syndrome (FAS), in which she eloquently addresses the issues of blame and guilt related to these syndromes, citing the question often asked by mothers, "what have we done wrong?" Of course, the drinking during pregnancy wasn't their fault as they were the adoptive parents. However, they found many other avenues to self blame, i.e. not recognizing the syndrome, not getting help soon enough, not getting the right help, being too strict, not being strict enough, etc. Buxton further illustrates the benefits of parents communicating, sharing, and educating themselves and each other through support groups and the internet. The style of the book combined narratives and factual information in a style similar to that used by Fowler (1993) in her book *Maybe You Know My Kid*, where each chapter is composed of three parts – autobiography, factual and summarization. *Special Parent, Special Child* (Sullivan, 1995), is a collection of six moving stories of parents of children with various disabilities, such as cerebral palsy, blindness, life threatening illness, hearing impairment, learning disabilities and Down syndrome, chosen from over 200 interviews. The author himself is visually impaired and therefore shares some of his own insights. In the first chapter of this book, he writes about his own mother's difficulties and triumphs in raising him, a blind child.

Although this book is very helpful, it certainly illustrated the limitations in this style versus the autobiography where the mothers opened up their hearts, their souls and their minds, to share the intimate and intricate details of their lives mothering a child with special needs. Ann Ford, the great granddaughter of Henry Ford, learnt in the 1970's that her daughter Allegra's differences were the result of severe learning disabilities. In her book, *Laughing Allegra*, Ford (2003) described how she faced challenges that many other mothers have been forced to face. However, she states that even her money and her position could not ease her pain or help her with her struggles. Her candor in that statement is very important in highlighting the extreme pain that mothers feel, a pain that cannot be easily relieved. This particular autobiography is interesting as it is written in 2003, thirty years after her daughter was born. The author's stories are almost like a historical account, illustrating the major differences between her struggles and her involvement in her child's education and therapy and those of mothers in the 21st century. At times, she mentions that it is different for present day mothers. However, it is a very interesting to read her story in comparison to the stories that are written in the present about very recent events. It is an excellent document to be used for understanding the emotional turmoil that a mother goes through when she is faced with her child's diagnosis and the lengths that she goes through to help her child. Her document also illustrates memory work as she searches her memory, retelling stories and exploring feelings that she had three decades earlier. Finally, the fact that she wrote her book thirty years later, whereas most of the current autobiographies are written within the first five to ten years of the child's life, is further evidence of the increasing popularity – and need – for writing and publishing one's autobiography, with the potential goals of making a

difference, telling one's story, helping others in similar situations and sometimes educating the educators and health professionals. Temple Grandin's mother has also recently written a book about her daughter, a woman who suffers from high functioning Autism but went on to receive a PhD in animal sciences (Cutler, 2004). Grandin wrote many books herself describing her own experiences. However, her mother only recently wrote the story from her perspective. It is interesting that Grandin's mother did not write her story in the 1950's and 1960's while she was experiencing raising a child with Autism or even in the 1970's or 1980's when the memories were fresh. The early 21st century has seen a somewhat literary explosion in autobiographies written by mothers of children with special needs. Perhaps Grandin felt a need to share her story, even after so many years, as she wanted others to read about what it was like in the pioneering years of Autism, a sort of historical perspective. Or maybe as her daughter has been quite successful academically and professionally, in spite of her obstacles, she felt she could give others hope through reading her story. As with Ford, her story shows the historical perspective and the product of memory work.

Reading about other mothers who have successfully treated and at times "recovered" their children can be inspiring, motivating and encouraging, offering ideas and hopes, stimulating dreams. However, if the mother is not able to help her child to recover - for financial, emotional or other reasons and/or if the mother is not successful in her efforts - her emotions related to stages of mourning (i.e. denial, anger and particularly guilt, may be increased dramatically). The age and stage of the child, the stage of the mother's mourning process and the interactions between these, may have an impact on the mother's emotions.

While reading and reviewing this growing field of writing, I noticed new issues emerging in the more recent books. *Unravelling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery* (Seroussi, 2000) and *Like Sound Through Water: A Mother's Journey Through Auditory Processing Disorder* (Foli, 2002), both deal with parents who communicate and share on the internet. These mothers describe their frustrations in their efforts to receive the appropriate services for their children. They describe their frustrations and even panic, in realizing the general lack of knowledge in the field. They write about their beliefs around the necessity to understand their children's conditions, and to find the appropriate assistance (i.e., therapy and education). By using the internet and reading anything they could find; books, magazines and journal articles, these mothers gained valuable information. They suggested that being armed with information made an incredible difference in each of their children's lives and therefore in their own lives. Sharing of information on the internet and sharing their stories through writing, appears to have made a difference for other parents as well. These writings in some way have helped to guide future trends in research and treatments. That is, parents who support each other by sharing information and by advocating for their children have influenced researchers and policy makers by making their collective voice heard. This realization was reinforced by the participants in my writing groups, who shared an enthusiasm in writing a book of our own, with the hope that they may "help other mothers" and "maybe make some teachers, doctors or others understand just a little more ..."

Helping Oneself by Helping Others

The authors of those books, like the participants in my study, expressed feelings of anger, guilt, frustration and confusion, to name only a few emotions. They described how reading, writing and storytelling, helped them to heal themselves. They also expressed their need to share with others, to make a difference and perhaps to find positives in situations that often seemed negative. I began to wonder whether the beneficial elements involved in the writing of these books was about telling one's story for the benefit of oneself, or telling one's story for the benefit of others. In the book *The Story of Jane Doe*, a woman tells her story 16 years after she was raped by a serial rapist, and then sued the Toronto Police Department for negligence (Doe, 2003). The author says that writing the book allowed her to finally tell her story, her way, after so many years, but it also allowed her to tell others about what happens when a woman is raped. Both these aspects were integral to motivating her to sit down and write her story. Moreover, writing about it wasn't the only element of importance; telling the story over and over again as she made cross-country tours became part of the healing process. Giving birth to a child with disabilities or receiving the diagnosis that one's child is chronically ill and/or disabled can certainly be traumatic. Many of the events related to this may also be considered traumas, i.e. medical crisis, disappointing test results, endless complaints from teachers, calls from principals and "professional heavy, mother blaming" case conferences. That is a group of individuals, theoretically composing a team that could include educators, principals, special education consultants, social workers, psychologists, psychiatrists, speech and language pathologists, and/or occupational therapists in addition to the parents. The parents, particularly the mothers,

often complain that they feel blamed for their children's difficulties, particularly social and behavioural problems. After many of these "traumas" (i.e., the diagnosis, the medical emergencies, the school meetings), telling and retelling her story, even when it's ostensibly for the benefit of others, is often a mother's way to maintain her own sanity.

Helping Others by Helping Oneself

By writing about our lives, particularly in relating to the lives of those who are close to us, we may begin to unconsciously make connections, as we travel through our memories and impressions. In her autobiographical *My Name's Not Suzie: A Life Transformed by Literacy* (Hamilton, 1995), the author explains how in our writing we articulate these connections as they become "the stepping stones in the river of our reading and through the forest of our experience" (Hamilton, 1995, p. 70). These stepping stones may connect ideas and events and they may guide our efforts to define and redefine our lives.

Hamilton illustrates the importance of storytelling in making a difference in society and in giving people hope. She suggests that these basic acts of literacy, that is reading the encounters of others with internal and external problems, and writing about our own internal and external problems, can contribute to the resolution of tensions on a personal level. She suggests that we write in part to arrive at our own resolutions of turmoil and that we discover that our own personal resolutions may extend outward to the resolutions of larger parts of society. She uses her own book as a case in point. Writing it, she explains, contributed to her own deeper understanding of herself, her family and her students, as well as her work teaching at a University. She states that if one person who

reads her book comes away with a more positive attitude towards children who have been prematurely labeled uneducable or socially inept, and if that person begins to understand the role that reading and writing can play in helping children envision possible worlds that fall beyond their immediate environment, then she believes that her book would have gone beyond her own immediate ability to contribute to the lives of these children. She suggests that if multiplying this by 10 or 20, the possibilities for personal acts of self-understanding to influence other people becomes almost boundless. This feeling of advocating through writing appears to be gaining popularity as many individuals find hope and comfort in the idea of reaching others, teaching others and advocating for others.

I was pleased to read the words that Hamilton wrote as I often feel the same convictions and think similar thoughts. The women I wrote with (i.e. participants in my study) echo these same thoughts as well. We often talked excitedly about how great it would be if even one mother was comforted and /or inspired by our writing. Perhaps even more driving was the hope that a doctor, teacher or even another child in the schoolyard, would read our words and reflect before they said or did something hurtful. Hamilton explains that writing and reading are not to be solitary ventures. They need to be shared, discussed, questioned and elaborated upon with friends, families and colleagues. This was a further inspiration and validation for the writing groups that first developed in my clinical practice, where we wrote, read and elaborated our stories to each other, for each other, and for ourselves.

Truth in Fiction

One of the questions I was interested in was whether there are differences between reading for pleasure, to acquire knowledge, to find resolution or as a means of therapy. In *Reading to Heal: How to Use Bibliotherapy to Improve Your Life*, author J.D. Stanley discusses the value of reading fiction as a form of bibliotherapy. Stanley suggests that just because the story the writer shares did not actually happen, it does not mean what is written is not truth (Stanley, 1999). This is an idea I feel needs to be addressed and reflected upon. In reading fictional diaries and memoirs and often in considering the biographical data on the author and the sources for information gathering, for example observation and interview, it becomes quite evident that the fiction is indeed based on fact and of course on the interpretations, perceptions and memories of the author. This information is often full of truths and information on a situation and/or phenomena being exposed. As Joseph Gold discusses in his book *Story Species* (2002), the true story is that which we believe in.

While I was working on this thesis a client suggested I read the novel, *I Don't Know How She Does It: The Life of Kate Reddy, Working Mother* (Pearson, 2002). This is a fictional story about Kate Reddy, written in the form of a diary. The client who suggested this book described how she "laughed aloud while reading it." My initial reaction was that it will take time from my reading to complete my literature review. However my curiosity was aroused and I felt I could use some "relaxation reading." I was very pleased that I did read it, as I began to explore my thoughts on the value of fictional readings and to the meaning of the expression "there's truth in all fiction." The book is about Kate Reddy, a high powered financial consultant living in London, with her less

successful husband, her five year old daughter and her one year old son. Her diary entries reflect her struggles, that is, not fitting in with the "boy's club" at work and certainly not fitting in with the "Muffia" (stay at home, bake-your-own-pies mothers), while struggling with her own guilt, insecurities and fatigue. In this book, referred to as fiction, many of the themes were familiar ones in the research on mothering-for example mother blaming, good mother/bad mother, mothers' need for nurturing, ambivalent feelings towards the child, fears and guilt - all successfully portrayed in an entertaining yet "eye-opening" way. Kate's frequent nightmares of being judged in court, with regards to her mothering abilities, is a truly brilliant illustration of the intense feelings of insecurity and confusion felt by almost all mothers, especially working mothers. One can only imagine how much more intense these feelings and insecurities must be for mothers of children with special needs and for working mothers of children with special needs.

The cover of the book illustrates a woman juggling a briefcase, a toy and a pet hamster. Her diary entries cover everything from charging into her daughter's Christmas play, high heels tapping loudly on the hardwood floors, to sitting in a board room full of male executives in New York City, scratching her itchy head while receiving a text message on her pager that her daughter had been sent home from school with lice. Other stories of disappointed in-laws, demanding superiors, frowns from the "Muffia" and crying children hanging onto mother's legs, could only be based on the collective stories that the author must have heard from others and/or felt in her own life.

Clearly, fictional stories based on collective experiences which are presented in an entertaining format may reach a greater audience. I wonder, however, are they more therapeutic-for example, by bringing humor to the situation? Or are they less therapeutic-

minimizing serious, hurtful issues and problems which are often not only serious but overwhelming? For mothers of children with special needs, how much greater is the impact of juggling priorities when medicines, therapies and reports are also being juggled in the air and how will this type of book help? How does the mother's stage of mourning at the time that she reads this book impact her perceptions and uses of the book? Could humor at one stage help achieve resolution and acceptance, but have a negative effect at another stage? As a reader, I see answers embedded in these fictional works. As a researcher, I see only more questions.

Letting Questions Lead the Way

There has been a dramatic increase in magazines, reference books, non-fiction books, self-help books, autobiographies and fiction, written for mothers and often for mothers of children with medical disorders and/or disabilities. This increase in publications provides a strong indication of the need and value of reading for therapy and support. If reading is helpful, what about writing? I wonder why more and more mothers are writing their stories. Is it for therapeutic purposes, for advocacy, or to attain other goals and objectives? Also, if people benefit in different ways from different types of reading, do they benefit in different ways from different types of writing - for example, journal entries, poems, a story, or a letter?

While writing this thesis, I began to question the reason for the growing popularity of stories seen in books and magazines. I questioned whether any or all of these really help. If they help, is one format or style better than another? I began with a cursory search of the study of popular literature, with very little success. I was left with a

number of potential hypotheses, and many more questions. I feel this area is under-investigated at this point and yet rich with potential as far as the reasons for and benefits of this dramatic increase in popularity. I wonder if the emergence of the nuclear family to replace the extended family is at least a contributing factor of the increase in turning to books. Grandmothers and aunts once helped with the raising of the children. Now, parents are on their own. Women used to share child-rearing strategies while washing dishes. Sharing advice has diminished with the art of storytelling. Also, with the increased value placed on education, people seem to trust the written word (i.e. if it's written in a published text, then it must be true). Some have traced this present popularity to Dr. Spock's classic tome on childrearing (1946, reprinted 1963).This was a time, I might add, which was riddled with mother blame and proselytizing that mothers should be with their children 24/7.

As mothers continue to turn to the written word in increasing numbers, I see an increased need to look at this phenomenon and understand it, i.e. what needs they're trying to fulfill by reading and writing their stories, and whether these needs are being met.

Summing it up

Musician John Lennon sang "Life is what happens ... while you're busy making other plans." As I worked on my thesis, I moved at different paces; fast, then a bit slower, then picking up speed again. Every time I picked up speed, it seemed there was a bit of a crisis in my personal life. I often thought I'd never finish. I even questioned whether I should just give up. Yet, the experiences I was living with, the doctors, the guilt, the fear,

etc., usually made me realize that I must keep going, that this is very important work and that as I live the phenomenon, I must write about it. We are already in the 21st century, and yet I still witness many of the same situations as twenty or thirty years ago. I've seen some improvements in team work and in respecting parents, including mothers, instead of blaming them. Yet, I also experienced mother blaming, such as professionals insisting on mothers taking all the responsibilities and making hurtful, misconceived comments. I also realized yet again, how old emotions and interaction styles can re-emerge, after being dormant for many years. I've seen how old fears, frustrations, denial, anger, guilt, hopes and prayers can re-emerge as if they never left and become even more intense. A simple comment from a clergy member like "You realize at times like this that your work will be fine without you" can bring on feelings of "I shouldn't be working." The judgments, even in your favor, e.g. "I'll let you speak because you know what you're talking about, many parents don't" brought me personal relief, yet anger for the situation in general, (i.e. for those other parents). All the while, I kept thinking I must remember this, I must write it down.

What better way to introduce this thesis, then, than to share two recent stories. I recently obtained the name of a doctor who is highly respected in a very specialized area. She was recommended to us for our child with special needs and chronic medical conditions. I called for an appointment and I was told to fax the doctor's referral and if they wanted to give us an appointment, they would call. I was told that if my daughter was granted an appointment, it would take a minimum of two to three months. I explained that the referral from her doctor said very little and that I felt we needed to tell her story. I asked if I could send a letter of my own, along with the referral from the

doctor and I was encouraged to do so. I dictated a letter on the Dictaphone, allowing the thoughts to flow and adding information and events as they came to me. Then after the notes were transcribed, I highlighted and arrowed the various parts, trying to present them in a logical sequence. I wrote and I rewrote, until I felt the written document appropriately told the medical story in a proper sequence, with relevant details and necessary information. I left out all the emotion, as this was a factual, businesslike document. However, I felt the emotion of each event as I read it over, the words echoing in my head. In my mind, I kept wondering what would happen. Would the doctor appreciate my letter, or would she feel I had overstepped my bounds? After all, I'm "only" the mother. Would she trust my words as factual and accurate? I wondered about all this as it was most important to me, as my daughter's mother, to facilitate this consultation process. I also, however, found it interesting, as a researcher, studying writing and the impact of the written story. The writing, as I suspected, doing this research project, was therapeutic. It made me feel I was doing something worthwhile to help my daughter. I felt a sense of accomplishment in organizing and completing this document. I found it interesting how I first thought in my head, then spoke it aloud. Then, I needed to see it in writing to "work it." Finally, I wrote and rewrote until I was satisfied. I felt proud of my recall. It felt good to organize the events. I felt sad when I realized all that she's been through and all we've been through with her. I also feel that writing to doctors and teachers may facilitate communication and collaboration between parents and professionals. I, of course, read it to a friend for support and endorsement, then I faxed it off. The next morning we got a call, offering us an appointment the day after that. Our appointment was less than 48 hours after the fax had been sent. The following day we

met this bright, successful and very warm physician, who started our meeting by saying "Thank you for your letter, it was very helpful in gathering the facts." She further asked "are you a health professional as well?" I felt proud, yet I wondered what happens to parents who want to convey their messages but for a host of reasons, for example a lack of education or language barriers, they are unable.

The other morning I took a taxi to my teaching job. The same taxi driver had driven my son two weeks earlier to meet me at the college for lunch. The taxi driver began by telling me what a wonderful son I have: bright, mature, polite and so on. I thanked him as I proudly beamed from ear to ear, secretly proud to be thought of as a "good mother." Then he went on to explain his theory on child development, to tell me what a "good mother" I must be and how it's all up to the parents, at which point he corrected himself and said "actually it's all up to the mother." I thought of lecturing him on temperamental differences and all the other factors involved in the child's personality, behaviours and social skills. Instead I stopped myself, smiled and said "thank you."

I relate these two stories to illustrate the value of narratives in demonstrating a point. But also to explain how each and every day, whether at work, that is at my paying job, being a mother, attending a conference or even riding in a taxi, I feel more and more compelled, even driven, to research, study and teach the importance of reading, writing and storytelling, as an effective means of communication, a therapeutic technique, and a valuable qualitative research tool.

Overview of the Thesis

In this first chapter I have mapped out the autobiography of how I came to engage in the study of writing by mothers of children with special needs as a therapeutic and qualitative research tool.

In Chapter 2, I review mothering as a research area with an emphasis on the literature on mothering, particularly in the areas of the history of mothering, social construction of mothering, maternal ambivalence, good mother/bad mother themes, mother blaming, mothers and the child with special needs and finally, the stages of mourning.

In Chapter 3, I review the literature on reading, writing and storytelling individually and in interaction with each other. Specific attention is paid to the way that these techniques are used by mothers of children with special needs, individually and in support groups.

Chapter 4 discusses the methodology of the present study with an emphasis on the literature regarding focus groups, memory work, narratives and writing, as well as qualitative research tools and techniques. These pages review and highlight a special area of research, one that is still, in my opinion, not well enough respected, that is a style of research where the goal is about drawing on the experiences of all the participants, and working together to uncover memories and truths (perceptions) about a phenomenon, experience, or life event, and feeling good while doing it. The participants in this study, the data sources, the methodology and the data analysis are all discussed.

In Chapter 5, I highlight four mothers' stories; Sally, Chantal, Wanda and Belinda, particularly discussing pre- and post-project interviews, anecdotal comments,

the participants' individual writing and their feelings towards the work that they wrote. An analysis of specific themes around mothering a child with special needs and comments spoken or written regarding both mothering and writing are highlighted.

In Chapter 6, there is a discussion of key findings, with regards to themes and similarities in process and in content related to the research on mothering as well as the research on reading, writing and storytelling. As well, reflections of self as a participant are included and discussed. Finally, a discussion of the significance of this study, with regards to contributors, on the limitations of this study and on implications for future research are incorporated into this chapter.

Chapter 2: Mothering

In my search for literature on the theme of Mothering, I was initially drawn to books that I had purchased as a new mother in the early 1980's. Among the numerous books in my collection, Heffner's *Mothering* (1980) and Dally's *Inventing Motherhood: the Consequences of an Ideal* (1982) first introduced me to the concept of mothering in North America and its related movements and philosophies. The Feminist movement, for example, paved the way for novel opportunities for women who were made aware of the many options that lay before them. Ironically, the very choices that symbolized women's empowerment and liberation also often contributed to their sense of confusion and feelings of constraint.

As I proceeded to explore recent literature on the same theme, I noticed that numerous modern texts by such authors as Douglas and Michaels (2004) and Warner (2005), make reference to many of the same historical events and pioneers as the literature of the 1980's. These authors continue the story of mothering and of Feminism as the pendulum wavers each decade. They highlight such new issues as the effects of media on the Mommy Myth (Douglas and Michaels 2004) and the sheer insanity and tremendous anxiety of North American mothers (Warner, 2005). Elaborating upon such concepts as indulgent parents, baby-boomer parents, and working versus stay-at-home moms, Warner suggests that mothers are now in "The Mess", a position where they are searching for balance. Moreover, Beck (1997) asserts that while it is the best of times for women, it is simultaneously the worst of times. As Warner (2005) explains, although women have endless choices, the demands of motherhood often make it impossible for them to actualize those options. One can only assume that if mothers of "typical" children

are in a state of confusion or "mess", the state of disequilibrium of mothers of children with special needs – whose challenges are exponential - must be all the more heightened.

One of the objectives of this literature review is to develop an understanding of the social construction of mothering, in order to better comprehend the emotions and issues related to mothering a child with special needs. Reviewing the literature and gaining an appreciation of the past and present views on mothering and how the social construction of mothering has developed in North America, has been most helpful in honing my understanding of the complexities, frustrations, ambivalence and various other strong and often conflicting emotions that are felt by all mothers, but particularly by mothers of children with special needs. This review also helps us to empathize with mothers of children with special needs during such times as when their children are first diagnosed and as they continue to mother them.

Although a complete review of the history of mothering is beyond the scope of this thesis, this chapter would not be complete without considering the effects that historical events, past views of women, the inception of the feminist movement and the changing attitudes over the years around women and mothers had on shaping the social constructions of mothering. A number of key individuals have played a critical role in influencing the direction that mothering has taken. Amongst these individuals is Bowlby (1958), who stressed the importance of mothering 24/7 and instilled guilt in those who did not partake in his style of mothering. This paper has been influenced by a number of authorities including Crittenden (2001), Dally (1982), de Beauvoir (1949), Heffner (1980), Hochschild (1997) and Rich (1977).

Over the last two years, reviews specifically directed at the dilemmas, ambiguities, controversies and issues around mothering have been springing up more frequently. While Douglas and Michaels (2004), de Marneffe (2004) and Ellison (2005) all provide interesting descriptions of the history and issues around mothering, some authors have been particularly helpful at looking at the difficulties that mothers in academia encounter: Abbey and O'Reilly (1998) and Keahey and Schnitzer (2003).

A historical review of mothering children with special needs appears to be lacking in both the popular and professional literature. Interestingly, however, in the last century women have used books as a means of dealing with understanding mothering issues and also as tools to effect changes in their social status as well as their status as mothers. In recent years, it would appear that mothers and mothers of children with special needs are continuing to use literature with the aim of attaining the same goals.

I will review the literature on mothering and highlight how it relates to mothers of children with special needs as they assimilate the emotions, physical and psychological demands and sense of mourning inherent with the loss of the "typical" child who was eagerly anticipated, but never arrived. I will also review the social demands placed on this group of mothers and the social support (or lack thereof) that they currently receive.

It appears that mothering has become a discipline in and of itself: one which overlaps into many other fields, including Anthropology, Sociology, Biology, Psychology and Social Work, which are at the forefront. The importance of understanding mothering as an institution and realizing the need for support and information exclusively for mothers is underscored by such initiatives as The Association for Research on Mothering (ARM).

While there is quite an extensive body of literature on the subject of mothering in general, I have found that literature specific to mothers of children with special needs is less prolific. In my research, I was particularly interested in the literature on mothers of children with special needs, and in concepts such as mother blaming, the good mother/bad mother themes, mothers as advocates, relationships between mothers and professionals and therapeutic outlets for mothers, particularly in education and support.

In the discussions of mothering children with special needs, I will briefly describe some of the changes in society's perception, such as the gradual, albeit not complete shift from mother-blaming to an understanding of genetic determination and causal factors. This may be related to biological makeup, psychological makeup and certainly to the continued views and debates inherent in the social construction of mothering.

Social Construction of Mothering

One of the basic arguments surrounding mothering is the theory of social construction. There is a debate whether the act of mothering and all of its derivative components (i.e., the ability to mother, the nurturing aspect of mothering and the "need" to mother), are biologically ingrained in all women, or whether they are concepts that are socialized into a cultural mindset (i.e. learned behaviours shaped by the ideology of a particular society). According to Nakano Glenn (1994), much of how a woman defines herself as a mother comes from socially ingrained expectations, rather than from pre-set biological attributes.

Numerous cross-cultural studies that examine mothering roles with working class women, women of colour, as well as European women, illustrate examples that run

contrary to the accepted white, middle-to-upper-class American definition of mothering – which has elevated the role of mothering to one whereby the only person truly responsible for and capable of raising a child is a mother (Arendell, 1999). As noted by Nakano Glenn (1994), the notion of what it means to be a "good mother" is rooted in sociological, historical and patriarchal constructs.

How then, does this perceived role of mothering, even in a modern society where the infusion of feminist thought has attempted to offer women alternatives to being the sole caretaker of their children, (i.e., how does this "idolized mother image" affect mothers who have children with special needs?) If mothers with so-called "typical" children feel conflicted, guilty, and/or ambivalent (Parker, 1997), then do mothers of children with special needs carry an extra burden? Is this reflected in the emotional and psychological state of the mother? How do they then cope with experiences specific to their situations such as when their child is not behaving the same as other children when they are playing in the park? How much greater is the ambivalence for a mother whose child has uncontrollable temper tantrums, or is frequently rushed to the hospital, or whose erratic behaviour has a negative impact on family dynamics? In fact, mothers of children with special needs are particularly vulnerable to having negative emotions, excessive reflection and critical self-judgment, and many researchers are beginning to look closely at the negative effects a child's disability can have on a family, particularly on the mothers, who typically, are the primary care-givers. (Seligman and Darling, 1997).

Crittenden (2001), in her book *The Price of Motherhood: Why is the Most Important Job in the World Still the Least Valued?*, explains and illustrates how mothers are disadvantaged and often forced to be dependants, in a systematic fashion, by a society

who successfully exploits the group of individuals i.e., mothers, who do what should be considered the most important work. She suggests that as the twenty first century begins, women may be approaching equality, but mothers are still far behind.

Rosenberg (1988) discusses mothering as work (i.e., "mother work"). She explains the implications and relationships of this work to stress and depression. She compares and effectively correlates post partum depression to burn-out, a phenomenon often experienced by people in stressed out work places and particularly in the health care professions. Once again this analogy is even more appropriate for mothers of children with special needs, where the job of mothering not only comprises the care and nurturing of the child but the supervision of the child's education, as well as the additional mental and physical healthcare needs. The greater needs and often additional care required to mother a child with special needs, is often analogous to health care professionals carrying a very heavy case load. Rosenberg further comments on the importance of women realizing that what they are doing as mothers, is work. "I talk about the job and the fact that the woman is the manager" (1988, p. 385). She discusses misassumptions of husbands, even those who are "nice guys", who don't realize that "helping is not the same thing as carrying the weight of responsibility that mothers carry" (1988, p. 365). The shift to the nuclear family, greater geographical mobility, segmented households as well as the ideology of family privacy, all contribute to the minimal "on-the job training from experienced workers" (1988, p. 386). Rosenberg discusses the potential consequences of a woman finding herself in a job where the unfamiliar can be a devastating and confusing situation. She discusses the "rich systems of social support" (1988, p. 386) offered by other cultures to women who have just given birth. As well, many of these other cultures

make a public statement illustrating the importance of a new birth and the belief that social attention needs to be focused on the early childcare. This is in contrast to the North American system of moving from the public realm of the hospital, an institution, to the private world of her household. The education and support offered in the hospital is less, the stay shorter, and the support at home usually less as well. Values and politics around the care and support of children with special needs and their families differs between cultures and religions as well (Seligman and Darling, 1997). The value and philosophies a culture places on children with disabilities will certainly have an effect on the mother's emotional status and adjustment. These attitudes differ between cultures and even within cultures between handicaps (Seligman and Darling, 1997).

When a mother is confronted with the knowledge that her child has special needs, many mothers feel the extra burden, and then often feel guilty about considering their child as an extra burden, particularly if the child has medical vulnerabilities. Some mothers are inspired by the goals, objectives and demands (i.e., extra care and scheduling, therapist appointments, home treatment plans and/or specialized diets). They may pull out their agendas and notebooks, begin researching the internet and embrace their roles as primary therapist, case coordinator, teacher, nurse and a whole host of other "very important" portfolios. Suddenly a career has emerged and there is "more justification" for her staying home or conversely, she may feel more guilty than the mother of a typical child because she has a career or job and cannot be the teacher, therapist, etc. This guilt may be compounded by therapists suggesting excessive numbers of hours in home therapy which is recommended to be done by "the mother" and only the mother, a drawback to the theories in the 1950's of Bowlby (1958), Spock (1963), and

others. Stacey (2003) describes her frustrations in being placed in the position of being the primary and supposedly the best therapist for her child with special needs.

An interesting phenomenon occurs when the mother is a professional in the field. She may work all day helping others, while the care of her child is being left to other professionals or not being fulfilled. Then there are the stay-at-home mothers who feel guilty that they cannot buy the "oh so promising" programs which will "cure" their child, because they don't work outside of the home and therefore don't earn a salary which in turn means they can't purchase those programs at "only three to five thousand dollars plus." I wonder about what these mothers do with their unanswered questions and unresolved feelings, in a world where they're not sure what is okay to think and to feel. They may worry about how they will be perceived. They may not even be sure of how they really feel or how they should feel. Maternal confusion and maternal ambivalence are concepts which have been studied, talked about and criticized for generations. However, the focus has been on maternal ambivalence in all mothers. My interest is in maternal ambivalence in mothers of children who have special needs.

Maternal Ambivalence

This confusion of how a mother feels has been termed "maternal ambivalence" and is a concept that has often been discussed and researched. Rich (1977) begins her chapter on "Anger and Tenderness" with a quote from one of her own journal entries written in November of 1960:

> My children cause me the most exquisite suffering of which I have experience. It is the suffering of ambivalence; the murderous alternation

> between bitter resentment and raw-edged nerves, and blissful gratification and tenderness (1977, p. 21).

This quote provides an excellent introduction to this section on maternal ambivalence. It illustrates the existence of two completely opposite poles of emotions to which the pendulum very often swings.

Arendell (1999) states that even the term "mother" can be ambiguous as it is used to refer to the person who physically gives birth to the child as well as to the one who actually performs the child rearing duties. This is a dilemma seen in many areas, particularly adoption. This concern is becoming more prominent each year, as issues such as new technology in reproduction are greater and more diverse.

Beck (1997), when referring to the end of the 20th century, suggested that "these are the best of times and the worst of times." She makes this statement as she suggests that women now have choices. However, she clearly illustrates how the choices are not always related to changes or advances in the perceptions of women or to any more positive outcomes. Many more recent authors discuss how our choices are not really choices (Warner 2005).

Ruddick (1995) in her book, *Maternal Thinking: Towards a Politics of Peace,* discusses how she first conceptualized mothers as people who see children as "demanding protection, nurturance and training" (1995, p. xi). She suggests that mothers attempt to respond to these demands with care and with respect, rather than with indifference or with assault. She suggests that this conception of mothering as a sort of caring labour, serves to undermine the myth that mothers are "naturally" loving. She discusses that maternal response is not preordained and those she refers to as "birth givers

or legal guardians," may respond to their children in a number of ways, including indifference, assault or active neglect. She further explains her belief that there is not a single emotion (i.e., love), that children inspire in their mothers. She suggests that a mother's emotions can vary over time. These variations in the mother's feelings may be related to the behaviour of her children, they may be related as well, to the space, time and services available to the mother and to a whole host of her desires and frustrations.

Therefore, aside from mothers dealing with their own ambivalent feelings, mothers also receive constant contradictory messages and their feelings may be continually changing in response to their individual child, with his or her own set of traits and behaviours and to the actions and words of others (i.e., society as a whole, other mothers, or professionals).

Ruddick suggests that some mothers are more "ambitiously reflective" than others. She postulates that this is either out of temperamental thoughtfulness, concerns related to moral and political issues, or as is most frequent, related to experiences of serious problems with their children. It is the latter that I chose to focus on. That is, that the mother who experiences serious problems with her child or children, may experience more reflection and more opportunities to feel ambiguous emotions related to her child and related to mothering itself. Ruddick also discusses how "favoritism in its many guises is a lively and fraught subject of maternal reflection" (1995, p. xiv). The ideas of fascination or significantly more negative emotions toward one or two or more children, appears to be a very critical issue of mothers of special needs children. They may resent, even hate the child with special needs or conversely they may feel an extra special place in their heart for their "special child" and indulge and overprotect them. They may want

to give them more love, attention and materialistic rewards as they feel guilty for the child's illnesses and/or disabilities, they may feel they must overcompensate for their perceived suffering or they may feel guilty about any negative feelings they may have had towards them.

Ruddick (1995) describes maternal love as "a mix of many feelings, among them: infatuation, delight, fascination, pride, shame, guilt, anger and loss" (p. xi). It would make sense to infer that this smorgasbord of feelings and the constant changing of these emotions from day to day or even from hour to hour, is more dramatic and intense when the child or children have special needs. With these children, the feelings can change almost from minute to minute and transitions, events, successes and failures are often more dramatic and more intense, for the child and often for the mother as well.

Heffner (1980) explains that mothers are not prepared for the kinds of negative feelings that they will have towards their children, and they often are not aware that these feelings are common to mothers. She discusses the typical anger felt, as a reaction to the stresses of childrearing. When reading about many of these emotions, anger, being an excellent example, it becomes apparent why difficulties in interpreting the mourning stages in mothers of children with special needs becomes a critical issue (see discussion in section on stages of mourning later in this review). Professionals are quick to suggest that a mother who has been told of her child's special needs is in denial or angry. However, these could also be related to feelings of ambivalence experienced by all mothers or a combination of the two (i.e., ambivalence exasperated by stages of mourning, or post-partum depression confused with and/or exasperated by the news of a child's diagnosis).

Arendell (1999), in her extensive review, states that the study of mothers has focused attention on a wide array of specific topics, and the relationships between these topics. These include issues of the well being of the mothers, further looking at distress, emotional work, social support, marital satisfaction, maternal employment and satisfaction felt about mothering. The status of the well being of the child was not discussed in her extensive review. This is interesting to note as it appears that "judgments" of good mother and bad mother, appear to be almost exclusively based on child outcome variables, particularly assessments of child behaviour and of child "success", rather than on criteria describing maternal traits.

While reviewing the literature on mothering, the many sources of ambiguity and conflicting emotions in mothers certainly becomes well understood and painfully clear. Mothers have been led to believe that it is a woman's natural instinct to nurture and to be and feel "maternal." Women who fail to feel this maternal instinct have been criticized, judged and frowned upon by some, while others have looked down upon women who accept this maternal instinct as their responsibility and their fate. It appears then that mothers feel ambivalence and society is made up of ambivalent and contradictory attitudes and views towards mothers and mothering. As Parker (1997) explains, the concept of maternal ambivalence is a contradictory and complex state of mind that is shared by all mothers in whom loving and hating feelings for her child(ren) exist side by side. Parker suggests that much of a mother's guilt stems from a difficulty in dealing with the painful feelings which may arise out of the mother's experiences associated with these ambivalent feelings. This is particularly evident in a culture where maternal ambivalence is strongly frowned upon. Maternal ambivalence may be even stronger when

the child has special needs and there is bound to be more anger, frustration, fear and disappointment, when mothering a child with special needs. Then there may be guilt about feeling ambivalent, when there should be complete love and maternal bliss. This guilt may be even stronger when the ambivalence is towards a child with disabilities. The mother may feel negative judgment from others and guilt regarding her ambivalence towards this poor suffering child. Finally, the fear of the child's well being may be more real than with mothers of typical children. Therefore, the guilt over any negative or ambivalent feelings may be even more intense. As with anger, these feelings of guilt may be complicated and/or confused by the guilt stage in the classical stages of mourning.

Parker admits that maternal ambivalence is a concept which is hard to believe. She explains how she herself questions the existence of such feelings. Parker chose to use psychoanalytic theory to explain this ambivalence, even though she recognizes that many feminists argue against psychoanalytic theory, stating that it is so full of "mother blaming" that it should be regarded as unusable. Parker suggests that psychoanalysis is an approach necessary for any deep understanding of this maternal ambivalence. However she further suggests that theorists must reexamine and rewrite the theories in an effort to highlight this theme more from a maternal perspective. Parker attempts to demonstrate how she uses conventional psychoanalytic theory, re-reading it completely from a mother's perspective. This is an interesting concept, as interpretations are very deep in subjectivity that is, the theorist's experiences interacts with his or her study. If the analyst and/or researcher is a male or even a woman without children, the study may yield theories full of subjectivity, frequently containing misleading and at times, false interpretations. I may add in the same vein that even a mother may provide theories

regarding mothers that are invalid with regards to mothers of children with special needs. An understanding of this is essential to understanding the importance of self study (Van Manen, 1990) by mothers and mothers of children with special needs. This review illustrates the importance of encouraging mothers to tell and/or to write their stories, in an attempt to better understand their experiences.

Parker (1997) points out the importance of environmental factors, as well as temperamental and developmental features of the child in influencing the degree of ambivalence a mother may feel. To illustrate this, Parker offers an example of a mother's responses to her school aged child who becomes ill. She describes how this mother, who was accustomed to mothering a child who attends school all day long, may now find herself in a situation where the child begins to cry when she leaves the room. Some mothers fall back easily into the role she terms "a life support system" and feel confident in this caregiver role. Some she suggests even prefer this, although they may feel embarrassed and/or guilty about their preference. However, she explains that other mothers may feel pulled back to a previous state of childcare which caused them fear and a feeling of claustrophobia; this too may elicit feelings of discomfort, guilt and/or shame.

This is so very true of mothers caring for a child with special needs. They may respond well to the extra duties, or feel bitter, resentful, angry, ambivalent and/or guilty. It is interesting to note that mothers who enjoy this revisited role or continuous role (i.e., from the neonatal period) of nurturance may be criticized for being overprotective, for fulfilling their own needs and a host of other such criticisms and focus of blame. Mothers who report and/or evidence difficulties in caring for their sick and/or needy child may be criticized and blamed for being negligent, cold, uncaring, unresponsive and/or unable.

The concepts of maternal feelings or the lack of maternal feelings and of love or hate or conflicting emotions, may be even more intense and often controversial when the child(ren) has special needs. These mothers may have more negative and/or conflicting feelings and feel more guilty about those feelings. Mother blaming is still a volatile, yet popular and widely utilized attitude. This is particularly widespread when the child has a disability and even more so when the child overtly exhibits behavioural and/or social problems. Mother guilt is a natural emotion, which is consistent with this mother blaming phenomenon. Finally, the themes of good mother and bad mother are natural consequences of judgment of mothers, mother blaming and/or mother guilt.

Good Mother/Bad Mother Themes

Dally (1982), in her book on mothering, wrote a very informative chapter titled "Fashions in child care." In her investigations of these "fashions", she reviews the writing on child care from hundreds of years ago through to the end of the 20th century, with its emphasis on everything from Hippocrates' *On Dentition* to the importance of hygiene, to the emergence of an interest in the emotional well being of the child, who had earlier on been viewed as "little adults." Warner (2005), cites Dr. Spock in particular, whose book titled *Baby and Child Care* had outsold "all other books in the history of publishing except for the Bible" (2005, p. 81). Warner describes Spock as an "unfeeling Patriach". Daily (1982), summarizes that the emphasis of all the writings throughout hundreds of years, was and still is always on what makes a "good mother." Dally herself uses the terms "good mother" and "bad mother" throughout her book.

Heffner (1980) discusses how the child who conforms is "good" and the child who doesn't conform is "bad." She continues to present the belief that a mother who "makes her child behave properly" is good, while the mother who lets her child "get away with it" would be considered a bad mother. In the introduction to her book "*The Myth of the Bad Mother: Parenting without Guilt*", Swigart (1991) states that before she mothered her own first child, she bought into the good mother/bad mother philosophy.

Price-Knowles (1990) discusses how everyone has an image of and some basic underlying assumptions about what a mother is. Price-Knowles elaborates on what these theorists have defined mothering to be, what they believe mothers hope to achieve in mothering and what women are required to do in order to achieve the level of a "good mother." Price-Knowles' discussion of good mother and bad mother terms is consistent with my own interpretations of the literature and my field research with mothers. Price-Knowles makes note of mothers identifying with characteristics and considering themselves as a "good mother" or a "bad mother." It is interesting to note that there is no mention of how a good mother is determined. However, the bad mother is determined by analyzing troubled adults and blaming the mother. This idea was nicely portrayed in a book by Mickelson (2000) who wrote about mothers of sons with behaviour disorders. It became very clear to me in my theoretical analysis of the literature, as well as my own research and data, that good mothers and bad mothers are determined by the outcome of the child (i.e., success and/or failures, health or disease), and not by the criteria related to the mother herself or to the mothering process. This is frustrating and ridiculous, as we continually find more evidence to suggest the influence of biological determinants on intelligence, personality, health and disease. However, even with these advances, mothers

can still blame themselves and are blamed for passing on "bad genes" for not realizing something was wrong with their child, and then for thinking or knowing something is wrong, but not doing enough about it. Amongst other fertilized "guilt grounds" are status of choices with regards to prenatal genetic testing, extent of prenatal care, and the level of medical or other types of management of the delivery. In the case of children with special needs, there are even more possible opportunities for feeling guilty, for example not doing enough, or doing too much. The initial phase of any evaluation includes the medical history. This always includes questions of the mother such as: did you smoke, drink, take drugs, take medications etc. during the pregnancy? This includes a backdrop of media publicizing the dangers of these practices. Many mothers respond to these questions, while asking themselves, "Is this my fault?"

Price- Knowles (1990) suggests that we need to develop a model of what the experience of mothering is actually like, not what the hopeful child inside of us all might have wanted, but what the grown woman experiences. She suggests that what is missing in the understanding of mothering is the extent to which it is a painful relationship and an exhausting, often thankless occupation. In the world of the media, art and literature, we are exposed to happy mothers. We are reared with the idea of children fulfilling us and yet with very little idea of how that should come about.

The body of literature on mothering and mother issues is vast. In recent more years, discussion has emerged regarding the "good mother/ bad mother" theme. Swigart (1991) discusses "mother myths" and other concepts. She encourages the idea of silencing the "mother myths." She also describes many negative feelings around mothering, and the guilt attached to having these feelings. Featherstone (1999) stresses

the importance of nurturing mothers, rather than blaming them. She also discusses that when mothers have feelings of hatred towards their children, or towards one particular child, they experience great feelings of shame. If they express these feelings, other people react in a negative way. Once again, these thoughts are very relevant to mothering children with special needs, as feelings of shame and hatred are even more likely. Feelings of excessive love and/or overprotection are also very common. A critical question becomes what is a mother to do with these feelings, as keeping them inside leaves them unresolved and may contribute to these feelings growing to even explosive degrees and/or contributing to increase likelihood of mental and/or physical illness on the part of the mother. Yet, expressing these feelings is risky with regards to the potential negative and often blaming reactions of others. Although the literature does explore the history and the nature of these issues, it does not appear to deal with what to do about these issues. As well, there is very little attention paid to mothers of children with special needs as a distinct and separate group.

Over the years, mothers' identities have changed and the concept of what makes a good mother has changed as well. Various trends have included staying home and baking cookies, working and serving as a "good" role model, being a super mom, volunteering at school, etc. Parker West (2002) describes the concept of the "soccer mom" – "the current leader in the conflict over the ideal 'Good Mother'." Parker West explains that the "Soccer Mom" stereotype can be described as a white female, of marital status, moderate to conservative in political orientation and a stay-at-home mother. Parker West describes these mothers as "June Cleaver in a minivan." Parker West explains how she sees this as the early 21st century answer for the stay-at-home mom. However she explains that while

June Cleaver typified the housewife, the soccer mom is a full time mother who is not concerned with her housekeeping responsibilities. The soccer mom is a mother first and all other roles take a back seat.

Parker West discusses this new approach to the ideal "good mother" identity. The mere idea that mothers need these kinds of identities is a sad statement in of itself, particularly when you compare it to the lack of a counterpart in the understanding of any other familial status.

Villani and Ryan (1997) found that some full-time mothers can experience a "mother crisis" when their perceived failure to meet the "Good Mother" expectations reaches a level of distress. There is also evidence that full-time mothers are more likely to experience symptoms of depression and anxiety than employed mothers. A comparison of levels of anxiety and depression in working mothers versus stay-at-home mothers, where in both cases the child or children have special needs, would be interesting.

The soccer mom identity may be seen as an advancement and maybe even a solution for many mothers. However, I can't help but wonder what this means for the mother with a child who has special needs. What happens when the child can't play soccer or can join the team, but is sneered at, criticized, laughed at and/or left out, even yelled at by other players or the parents of other players? Frustration, anger, guilt, shame, isolation, alienation and all the other emotions may run rampant. This usually results in more advocacy, more pain, more denial, frustration, guilt, etc. It doesn't appear that the soccer mom identity will work for this group of mothers. An integral aspect of the good mother/bad mother theme is that of judging mother and of course blaming mother.

Mother Blaming

Douglas and Michaels (2004) in their extensive review of mothers as portrayed by the media wrote as follows: "while any unusual trait that could be cast as an abnormality was the mother's fault, the father's role was hardly ever discussed, let alone criticized" (2004, p. 67). Mothering within a cultural and sociological framework is important to study when looking at what it is to be a mother, especially in the white, middle and upper class North American milieu. It is within this social context, that common ideology has evolved to render mothers as the sole caregivers to their children, if their children are to grow up healthy and balanced. Furthermore, it has been suggested that this "career" as a mother is one that women should embrace wholeheartedly and with enthusiasm. If there is a problem with the child, it is always said to be the fault of the mother. This sentiment is expressed in Caplan and Hall-McCorquodale (1985):

> ...too many clinicians still clearly hold mothers responsible for making or breaking their children. Even when the term "parents" is used in discussing the children's pathology, often only the mothers are noted in descriptions of interactions and illustrations of problems. (1985, p. 611).

This situation continues into the twenty first century. "Feminists were also wary of the tendency in psychology and the culture at large to blame mothers for a variety of ills — from troubles of their children to the problems of war, crime and poverty." (Chodorow, 1982). Lerner (1999), suggests that mothers are quick to feel responsible for everything. In their research into *Scapegoating of Mothers: A Study of Mother-Blaming in Case Studies Included in Core Foundation Social Work Practice Textbooks*, Ruffolo, Sugamele and Taylor-Brown (1994), suggest that blaming mothers for the behaviours of

their children is ingrained in the perception of professionals in the field of social work, perceptions that are often reflected in the attitudes of society in general. That is, mothers are responsible for the behaviour, development and eventual outcome of their children.

Dally (1982), argues that the notion of mothers staying home full-time with their children not only did not exist previously, but it was not natural. She suggests that large numbers of mothers who had never before the mid-twentieth century been isolated with their small children for most of their waking hours, suddenly found this to be the new norm. Being with children exclusively was seen as essential to the healthy psychological development of the child. It was further suggested that this was a demonstration of feminine normality in the mother. Dally pointed out that at that time there was no scientific evidence to justify this type of mothering on psychological grounds and that if one wanted to look for evidence, one might even come up with the suspicion that "the era of unbroken and exclusive maternal care has produced the most neurotic, disjointed, alienated and drug-addicted generation ever known" (Dally, 1982, p. 10). As well, she argues that prior to the medical advances of the late 19th and 20th centuries, babies were not expected to live long lives, or even live at all, so the modern-day notion of having a healthy baby and giving it 100 percent of a mother's attention did not exist. Because of this, Dally suggests that the role of mothering differed from what is expected today. Babies died so frequently, that mothers were not to blame - the environment, nature, even God, took responsibility for infant deaths and deformities.

With advances in modern medicine and technologies, mothers of children born with defects are now made to feel guilty if something goes wrong during their pregnancy and/or delivery. They are blamed if the diagnosis of a disability is believed to be the

outcome of poor prenatal care, poor delivery or even a lack of appropriate mother-infant bonding. The frequent questions around the pregnancy and delivery such as did the mother smoke, drink, take prenatal vitamins, and so forth, serve a purpose, yet contribute to the mothers' feelings of guilt.

Perhaps every issue that mothers must face has even more dimensions, complexities, and emotional impact in relation to children with special needs. Take for example reproductive technologies such as amniocentesis, ultrasounds and highly specialized blood tests. These modern options carry with them "pro-choice, pro-life" type ethical dilemmas with regards to prenatal screening and the right to life for those with handicaps. Beck (1999), in her autobiography entitled *Expecting Adam* discusses the reaction of anger and even repulsion on the part of the medical personnel, when she chose to continue her pregnancy with her son diagnosed prenatally with Down syndrome. Questions regarding whether one's life is more or less worthwhile begin to emerge. This is an excellent example of discrimination for children with disabilities and how blame towards parents, particularly towards the mother, can begin as early as the pre-natal stage.

Another perspective is that knowing one is going to give birth to a child with special needs means the mother is aware that she is in for possibly more heartbreak, more work, more time invested and perhaps a harder and longer job than she had signed for, yet the mother may be judged, criticized and frowned upon for choosing not to sign on for the job. These issues make us aware that all the dilemmas that the literature on mothering refer to may be exaggerated when the child has special needs.

Caplan (1990) describes a panel she organized in 1988 at the Goddard College conference on motherhood. The topic for the panel discussion was mother blaming. The

reason she chose this topic was that she and her colleagues were "stunned and deeply pained by the degree of mother hating" that they had witnessed in the ten years prior to the conference (1990, p. 61). She described being particularly pained when they saw this attitude in women, and was even more distressed to see it prevalent among feminists. Consequently, her purpose in organizing the panel was to publicly identify and begin describing mother-blaming and mother-hating as a problem.

Caplan describes her feelings as similar to the child in the popular fairy tale *The Emperor's New Clothes* where she would wait at conferences to hear the final summary and formulation. When an effort was made to explain the causes of emotional problems in children, Caplan writes how,

> Almost inevitably, the mother was blamed for the child's problems, and whether she was described as cold, rejecting and castrating or as overprotective and smothering, the description of her usually bore little resemblance to the women I had seen with my own eyes. (1990, p. 62)

She then points out that we need to ask ourselves, why the tendency to automatically look to the mother? It is interesting to note that regardless of the mother's style, others can always find a way to blame her. Whether overprotective, or negligent, over involved, or disinterested, the mother is pointed at and blamed, based on the behaviours of her child.

Caplan and Hall-McCorquodale (1985) document an extensive prevalence of mother blaming found in major clinical journals. They report their detailed exploration of the literature and illustrate the common practice of psychologists and psychiatrists to study disturbed children, rather than healthy ones. Once again, this has not changed significantly since that time. Caplan (1990) suggests that mother blaming is expressed

through myths about mothers, specifically the "perfect mother myth" and "bad mother myth." She suggests that no mother can ever meet the perfect mother criteria and therefore, mothers are set up to be disappointed and infuriated, as it is impossible to measure up to the accepted ideal. She suggests that the bad mother myth leads people to mislabel a mother's not so great behaviour as horrible and a mother's neutral behaviour as bad. These issues are even more significant for mothers of children with special needs, as it is so much easier to point a finger when both the mother and child's behaviours may be more open to being seen as bad and even horrible and where the perfect mother myth seems even more distant.

Ruddick (1995), in the preface of her book *Maternal Thinking: Towards a Politics of Peace*, candidly admits to her serious omission when she discusses children's demands while assuming that the children are "intact." She credits McDonnell, who after hearing her speak, pointing out that using the term "intact" as meaning: "not handicapped in some way, not blind, deaf, autistic, retarded, paraplegic, dyslexic, etc" (p. xv) but in contrast, being assured of typical growth, development and "minimal acceptability." Ruddick discusses McDonnell's eloquent descriptions of mothering a child with Autism and her calling into question Ruddick's apparent assumption of typical development. Ruddick presents McDonnell's narration in the preface of her book. She portrays the experiences of mothering a "different" child and how this may be seen as a matter of degree. She describes this as a significantly greater, intensified version of the bad days described by mothers of typical children, those mothers that Ruddick reports are dominating the pages of her book.

Ruddick discusses the concept of "stigmatization" and the rejection of "failed babies." Ruddick expresses her gratitude to "the many eloquent mothers and advocates of stigmatized, deprived, terrorized children" (1995, p. xvii) by crediting them for "telling maternal stories" which she explains are radically different from her own. This statement points to the lack of inclusion and understanding of the subculture of mothers (i.e., mothers of children with special needs). It also points to the importance of storytelling as a strong research source when trying to understand a phenomena, a situation, a group, or a culture.

Nakano Glenn (1994) discusses issues such as special accommodations for women because of their "unique responsibilities i.e., the physical and the emotional aspects of mothering (i.e., carrying, delivering and then caring for the children). If mothers involved in childcare are accommodated in typical situations, should mothers of children with special needs be given appropriate accommodations for the extra time needed for more appointments with doctors and therapists, as well as the often daily hours of therapy, training, special meal preparations, and so forth? Nakano Glenn discusses the developmental researchers' discovery of maternal bonding, a concept suggesting that it is essential for the infant to have a single care-taking figure, preferably the biological mother, in order to develop a healthy sense of self and an ability to relate to others. This work was instrumental in driving the mother blaming research, which was deeply developed and spread by the psychoanalytic group and strongly promoted by medical personnel and politicians. This trend was very popular following a research project by John Bowlby, commissioned by the World Health Organization and first popularized in 1951. It should be noted that Bowlby's work was based on his studies of

institutionalized children who were deprived of much more than their biological mother. Many childhood psychiatric disorders were being attributed to poor mother child bonding in early infancy and some psychoanalysts even developed what they called holding therapies to achieve a developmental stage or process they claimed was missing. Mother blaming was particularly apparent in the autism research. Kanner (1943) is well known for coining the term "Autism", offering specific diagnostic criteria. For this disorder, Kanner strongly suggests that the underlying cause of autism was having a "cold and distant mother", a phenomenon referred to by Kanner as "refrigerator mother."

A whole generation of mothers embraced Bowlby's ideas, if not with discomfort, then at least without evidencing any serious questioning or protest. His research conclusions were that an infant and young child need to experience a warm, intimate and continuous relationship (i.e., 24 hours a day, seven days a week) with its mother (or permanent mother /substitute) in which both mother and child obtain satisfaction and enjoyment. In other words, it was interpreted that Bowlby suggested that almost any mother is better than no mother at all and if one is thinking of orphans, and abandoned children this is obviously true. He was also suggesting that mother not only be there 24/7, but that she obtain satisfaction and enjoyment from it. There was no discussion of fatigue, cabin fever or any of the emotions previously discussed for example, ambiguities, fears or frustrations. Mothers took Bowlby's advice very seriously, considered this a central aspect to being "a good mother" and worried that if they were not with their children at all times, fulfilling their needs, they might cause serious damage to their children. To this day, Bowlby's attachment theories are still being taught in child development courses.

Perhaps one of the biggest influences and initiators of mother blaming began with the advent of psychoanalytic theory, where Freud blamed the outcome of an individual's mental health on their relationship with his or her mother. Professionals and lay people alike embraced his ideologies, holding mothers responsible for every fault of their children.

I can only emphasize how the idealization of mother may present an even greater impact and concern when the mother is taking care of a sick and/or handicapped child. The importance of spending 24 hours a day, seven days a week is often stressed even more for this group in the 21st century. The disillusionment and emotions that go along with mothering when a mother has a child with special needs, may be even greater. Although these ideas of 24 hours a day, seven days a week were changed to some degree with the feminist movements and changes in women's roles, these ideas of constant care and responsibility continue to hold true with a population of mothers of children with special needs.

In 1998, Judith Rich Harris, in her book *The Nurture Assumption: Why Children Turn Out the Way They Do*, tried to tackle the nurture assumption and remove some of the focus on mothers being responsible for all that her child becomes. She proposes that the notion suggesting that children turn out the way they do as a result of the way their parents bring them up is nothing more than a "cultural myth." She focuses on other experiences outside of the home such as, socialization with peers as being an important consideration in the understanding of the development of the child. Her controversial theories gained much popularity in the years that followed. However, the controversy continues and mothers are still often blamed for the weaknesses and negative behaviours

that their children exhibit. Once again, this is particularly evident with children who have behavioural and developmental disabilities.

Mothering and the Child with Special Needs

Mothers of children with special needs are particularly vulnerable to negative emotions, excessive reflection, and critical judgments of self. Many researchers (Ong, Afifah, Sofiah and Lye, 1998; Baker and Heller, 1996; Crowe, Van Leit, Berghmans, and Mann, 1997; Pithers, Gray, Busconi, and Houchens, 1998; Hughes and Caliandro, 1996; St-Onge and Lavoie, 1997; Lustig, Ireys, Sills and Walsh, 1996; Stewart, Ritchie, McGrath, Thompson and Bruce, 1994) look closely at the adverse psychological impact of a child's disability on the family, particularly on the mothers, who assume the majority of the caregiving burden (Lie, Borjeson, Lagerkvist, Rasmussen, Hagelsteen, and Lagergren, 1994; Crowe, Vanleit and Berghman, 2000). Amosun, Ikuesan, and Oloyede (1995) discuss the stress of mothers of handicapped children, and state that addressing psychological disturbances in caregivers should form an integral part of the treatment of handicapped children.

Stallard and Dickinson (1994) suggest that even though the impact on the family following a child's diagnosis is significant, the parents report feeling that their needs are not specifically addressed by professionals. They describe a series of groups for parents of pre-school children with severe disabilities. Throughout all these studies, mothers of children with special needs are found to be at risk for such emotional problems as anxiety, stress, hostility, and depression.

Gartner and Schultz (1990) in their paper entitled *Establishing the First Stages of Early Reciprocal Interactions Between Mothers and Their Autistic Children*, begin their chapter describing the reciprocal nature of early mother-child interactions and the effects this reciprocal relationship can have on the mother (Bell and Harper, 1977). They describe what occurs between an infant and a mother who is sensitive and aware, describing a bidirectional relationship. The authors explain how when this early interaction process is halted from being set into motion, serious problems develop between the mother and her infant. Robson and Moss (1970) describe the vicious cycle that ensues when the mother is unable to comfort her baby and is unable to establish eye contact. The mother's efforts to deal with the crying infant are inadequate. The infant responds by crying more which causes the mother to withdraw even more. The mother often reacts by feeling angry and hurt. She feels her baby is rejecting her and she interprets this to mean that she is failing as a mother. The shame and humiliation of this can be extremely painful to the mother who then withdraws even further from her baby. This can be seen as an angry or hurt reaction or as a sensitive response to a child's discomforts. The latter is rarely the interpretation of the outside observer. Gartner and Schultz explain how infants with autism form little to no eye contact, are often unaware of and/or unresponsive to the efforts or even the presence of their mothers, rarely smile and hardly ever initiate any contact. It is postulated that those behaviours serve to frustrate the mother, as she doesn't receive any pleasure and pride and may feel incapable of providing her own child with comfort. This role of comfort agent is one that the literature often suggests as an essential characteristic of a "good mother." It can therefore be seen how when the child cannot achieve the "typical", even basic, tasks - for example,

making eye contact, the mother may feel less "good" and subsequently drive the objective of being a good mother even further away.

Gartner and Schultz discuss how these theories which explore the notion of bidirectional relationships and mothers responding to the child's cues, offer a very different point of view from the earlier theories. They point out how these false theorizations, like Kanner's "refrigerator mothers", caused "needless heartache and guilt in generations of mothers, often, unfortunately, reinforced by professionals" (1990, pp. 161-162). Their article provides an excellent illustration of where professional theorizing and interpretations can contribute significantly to the continuation of mother blaming, and the triggering of mother guilt and insecurities.

In discussing how an entire family is affected by a family member with a disability, Seligman and Darling (1997) focus on the constraints in drawing conclusions from the available research. They caution against arriving at misleading conclusions. They suggest however, that the "sense" one may interpret from the available professional literature is that "the trauma and unrelenting stress of coping with a youngster who is disabled can be difficult at best if not immobilizing" (1997, p. 89). Seligman and Darling included the following quotes to illustrate their points:

> Some parents overprotect and do not stimulate the child to use the abilities he has. Others are so depressed that they cannot do much for the child. In still others, the sadness is interwoven with a kind of impotent rage toward the world. Many parents are angry at the retarded child, though they try to cover this up, hating to admit feelings of anger toward a helpless child. Most try to do their best in spite of their personal sense of loss and

> sadness, but some become cool and distant and withdraw from the retardate the sustained warmth and stimulation that he requires even more than other children. Some parents try to quash their own sadness and embark on brisk programs, pushing the children relentlessly toward speech training, toilet training, nursery school, exercises, and a host of other "stimulating" activities. If they push too hard, they overwhelm a vulnerable child and tend to make him withdraw even further. (Bernstein, 1978, pp. 58-59)

An interesting observation is that Bernstein appears to be presenting extremes, all portrayed as negative. The mourning stages are well documented: rage, loss, anger, withdrawal. However, in all cases, the parent behaviours are seen as extreme and pathological.

The following is another quotation used as an illustration of the professionals' views on parents in Seligman and Darling (1997, p. 90). This quote illustrates in what appears to be a non-judgmental fashion, the many challenges, emotions and difficulties that parents who have children with special needs may confront:

> Families with a chronically ill child confront challenges and bear burdens unknown to other families. The shock of the initial diagnosis and the urgent and compelling need for knowledge; the exhausting nature of constant care unpredictably punctuated by crises; the many and persistent financial concerns; the continued witnessing of a child's pain; tensions with one's spouse that can be aggravated by the fatiguing chronicity of care; the worries about the well-being of other children; and the multitude

> of questions involving the fair distribution within the family of time, money, and concern - these are challenges that parents of chronically ill children must face. (Hobbs, Perrin, and Ireys, 1986, p.80)

It is interesting to note the difference in tone between the first quote, written in 1978, and the second, written in 1986. This difference may be related to differences in the authors' orientation, or it may be related to the eight-year time lapse or to the fact that the first quote is describing parents of children with intellectual deficiencies and the second quote deals with parents of children who have chronic illnesses. Mothers' feelings may be the same in these two situations and/or very different. The second quote appears to focus on the difficult emotions families must encounter and deal with, whereas the first quote appears to highlight the extreme behaviours towards the child, that is, overprotecting, pushing or ignoring. Seligman and Darling (1997), in their extensive literature review, summarize that although the literature available at that time offers contradictory and inconsistent results, it strongly suggests that families of children who are "mentally retarded" are at risk for many more difficulties than families with typical children.

Patterson (1991) suggests that parents who have more health and psychological difficulties may experience a diminished sense of mastery. One may conclude that the latter is an essential element as that diminished sense of mastery further shakes the parents' foundation. Patterson further points to that fact that mothers appear to be more vulnerable when they feel the responsibility to personally absorb the family's stress and therefore attempt to protect the other family members from this emotional turmoil and stress. As well, she points to the fact that even though the divorce rate of these families

does not appear to differ significantly from other families, there does appear to be a higher degree of marital distress. It may be that there is more marital discord, commonly seen when there is a higher level of stress, decision-making and crisis. However, these same events may affect the couples' ability to make decisions regarding staying together or breaking up. The parents and more often the mother, must contend with caring for a child with special needs, while dealing with a difficult, often confrontational, marital relationship, which is frequently riddled with feelings of anger, guilt, blame and confusion.

Seligman and Darling suggest that much of the research to date has been obtained by concentrating on the mother's experiences, including her perspective on how other family members are feeling and reacting. Much of the early research was conducted on families with a member or members who were "mentally retarded," often to a severe degree. This trend in research is gradually changing. Seligman and Darling suggest that the more recent studies that are dealing with disabilities are including hearing impairments, epilepsy, chronic illness, spina bifida, autism, hemophilia and mental illness. It is interesting to find that the authors' conclusions suggested that these studies, although segregated by disabilities, implied that the various families studied were more dissimilar than alike. They suggest that further research should investigate variables such as the severity of the disability, chronicity, number of disabilities (i.e., medical and intellectual, developmental or physical, as well as intellectual), number of children with disabilities, number of other children, marital status, state of martial relationship, financial status (SES) and degree of support from family, friends and professionals, as a few of the many possible contributing factors.

Seligman and Darling also reiterate the fact that mothers have been the most often studied until the time they wrote their review. However, they suggest that this is changing as siblings, fathers and even grandparents and other extended family members are being studied more. They suggest that the understanding of families of children with special needs has been gradually changing from a singular focus that is, the mother, to an orientation that explores family dynamics as well as even more broadly based ecological factors. They strongly suggest that future studies consider "the multitude of influences on families and not resort to linear and simplistic explanations of family functioning" (1997, p. 91).

Central to all of the research is an understanding that parents of children with special needs experience many different emotions. Those emotions may come and go depending on their stage of adjustment as well as their child's stage of development and illness, diagnosis and treatment. The stages of emotions have been compared to the stages of mourning (Kubler-Ross, 1997).

Stages of Mourning

Seligman and Darling (1997) discuss the stages of mourning which parents are thought to experience after learning about their child's disability. They suggest that the practice of applying the stage theory to parents of children with disabilities has been subject to some controversy. They discuss first how stages can be confused conceptually merely in the name use, for example denial for one is maybe called guilt for another. As well, they discuss that most of the studies on these emotions were accomplished with participants who were white, middle to upper class. They believe that these mothers had

some education and experience in utilizing human services and they may be better at articulating a stage or reflecting upon the stage theory model that was proposed to them. The stages they discuss are in reference to families with children with disabilities. The use of the stages of mourning to describe a parent's adjustment to having a child with special needs is a result of the observation that the birth of an infant with disabilities is often experienced by the parents as the "death" of an expected normal, healthy, child. Seligman and Darling discuss the stages of mourning, that is, denial, anger, guilt, bargaining and acceptance (Kubler-Ross, 1997). They discuss that shock and denial are a parent's initial response. Denial appears to operate on an unconscious level towards excessive anxiety. They explain denial as a useful "buffering purpose" early on. They caution that this same denial, if it persists, can cause difficulties when parents may continue to deny the existence of their child's disabilities. They say that parents during this stage feel confused, numb, disorganized and helpless. I question whether the degree of this reaction is in part related to the time of diagnosis, that is, at birth, in infancy, when they start school or even later in childhood or adolescence. Some parents are unable to hear much of what is being told to them. They suggest that the bargaining phase is characterized by a type of magical fantasy thinking, with the underlying theme being that if the parent works really hard, the child can improve. This is based on the belief that a child's improved condition is compensation for hard work, such as being useful to others or by contributing to a worthy cause. During the bargaining phase, parents might join local groups and activities that benefit a particular cause, or they may turn to religion or look for a miracle. When they realize their child will not improve significantly, then anger may develop. It may be anger towards God – why me, or towards oneself, towards

the spouse who produced this child, towards professionals for not healing the child, towards teachers for not healing them or helping them to make significant gains. Anger can also come from feelings toward an unsympathetic community and insensitive professional, inadequate services, fatigue due to long hospital stays and so on.

Excessive guilt sometimes turns anger inward so that a parent, often the mother, blames herself for the disability and this can often turn into depression. Seligman and Darling discuss how expressing anger is often cathartic and cleansing and can reduce anxious feelings, but when parents realize that their anger does not change their child's condition, and understand the chronic nature of the disability, a sense of depression can also set in. Seligman and Darling talk about how depression can be temporary and/or episodic. However, some parents develop a chronic sorrow that they experience when they have a child with a disability. The depression may coincide with a particular stage of the family life cycle. Developmental transitions imply change and invite comparisons with other children and families. These periods are time bound. Entering school, (i.e., kindergarten), adolescence and adulthood appear to be three particularly vulnerable time periods. This is a very important fact as parents may wax and wane in between these emotions; they may come to a resolution and then once again be faced with differences and new challenges where they once again feel anger, guilt or depression. They also at times have a milder and more normal form of dysphoria. Seligman and Darling (1997, p. 95) suggest that acceptance is achieved when parents achieve the following characteristics:

1. They are able to discuss their child's shortcomings with relative ease.
2. They evidence a balance between encouraging independence and showing love.
3. They are able to collaborate with professionals to make realistic short and long-term plans.
4. They pursue personal interests unrelated to their child.
5. They can discipline appropriately without undue guilt.
6. They can abandon overprotective or unduly harsh behavioural patterns towards their child.

Seligman and Darling caution that when applying these stages one needs to remember that families are not homogenous and the stages may not be a good fit for some families. For many families, the stages are cyclical. They recur as new developmental milestones are achieved or when a crisis occurs. This could imply that even after achieving these six characteristics of acceptance, a parent or parents may lose some of these characteristics and return to the "mourning stages." For example, the parent may stop allowing time for themselves, indulge the child again or lose the established collaborative relationship with the professional. An interesting question is whether the parent who has found acceptance and lost it, will reach acceptance more quickly the next time.

Other factors that affect the manifestations of these stages might include cultural differences and expectations, whether all the family members experience the same stage at the same time, how long a particular stage lasts and what accounts for the differences and the durations. As well, there may be one dominant reaction, with other emotions

playing a less dominant role. There are many factors that may also affect or may be related to the stages and degree of stages: the chronic burden of the care, the stigma attached, marital stability, number of siblings, the different type of handicap as well as the severity of the handicap and the type of and amount of support i.e., financial, emotional, respite, both internal (within the family) and from external sources. It should be noted that the mother and father often go through these stages at different times and in different ways. A significant emotional impact is often on the mother, who takes care of the medical and educational needs of the child and is more often confronted with their own child and with other children (i.e., for comparison). The mother is also more often confronted with doctors, therapists and teachers and with their questions, diagnoses, verdicts and prognosis.

But while these stages in a traditional loss situation tend to be linear, that is, a person experiences a stage, accepts and then moves on to the next, mothers who have children with special needs often do not follow this pattern. Instead, they tend to flow back and forth between stages, depending upon the developmental advances – as well as the delays – that occur throughout their child's life. For example, a mother may reach a level of acceptance, until a setback at a particular stage in her child's development, or the entrance into a new stage of development (i.e., from childhood into adolescence, and adolescence into adulthood), puts her back into another stage, that is, anger, or denial. It is important that professionals working with this group understand these stages and how these stages can vary in type, intensity and duration.

When evaluating mothers of children with special needs in terms of the "stages of mourning", one must consider all the factors that come into play. For example, if the

diagnosis is given during the postpartum period, is there more likelihood for depression? This postpartum depression may be confused with some of the mourning stages or the mourning stages may be attributed to postpartum depression. There are so many factors to consider when trying to understand the feelings and behaviours of this group of mothers.

So all the dilemmas and dichotomies that exist for mothers are multiplied exponentially. These issues must then interact with external influences. that is, mother nurturing, mother blaming and support in time and in money and finally with the stage the mother is in at the time (i.e., denial, anger, guilt, bargaining, envy and so forth).

Women and mothers have come a long way, but the road looks to be still long and windy. Women are said to have so many choices now, yet there are still so many roadblocks.

Through this review I have seen how little we still know about the social constructions of mothering and the mothering themes when the child(ren) has special needs. I've also seen how writing about this is important for emotional resolution, advocacy and developing the history of this special group.

Chapter 3: Writing

In the previous chapter, I reviewed the literature on the social construction of mothering, as well as on issues around mothering such as mother blaming, mother guilt, ambiguity, good mother – bad mother theme, mother's feelings towards mothering and towards their children. These issues were highlighted as they relate to mothering a child or children with special needs. In this chapter, I will review the literature on reading and writing with a focus on how these activities may be used as an effective therapeutic intervention and a valuable research source for mothers, particularly mothers of children with special needs.

Regardless of the emotions the mother feels and regardless of how she handles these emotions and her situation, a recurrent theme is that the mother needs to tell and/or write her story as a way of dealing with her situation, problem solving and reaching catharsis. Many mothers feel the need to advocate for their children. Many need support and seek the support through reading and/or sharing stories. Douglas and Michaels (2004) in their book *The Mommy Myth: The Idealization of Motherhood and How it has Undermined Women* describes how motherhood has been defined in the media, primarily through books and magazines and how women turned to these books and magazines for many reasons including as a political tool, and for education and support.

Manguel (1996) quotes Diderot in the 1796 work, *Jacques Le Fataliste et Son Maître*, as saying "But who shall be the master? The writer or the reader?" This is much in line with the dilemmas still faced with studying reading and writing and the underlying interacting processes.

Bibliotherapy

In an attempt to fully appreciate the emergence of a popular self-help literature for parents, it is useful to begin by locating the reading within a framework that looks at what reading accomplishes. Reading itself has much to offer, from educational to therapeutic benefits. It allows for the gaining of knowledge and experience. It also facilitates finding escape and comfort. Manguel (1996) wrote an informative book titled *The History of Reading*, where he eloquently describes just that, the history of reading. His book is filled with stories both of his own passion for reading and of the passion for reading experienced by individuals throughout the centuries.

Manguel explains that it is the reader who reads the sense of what is written and who grants or recognizes in an object, place or event, a certain possible readability. He suggests that it is the reader who must give meaning to a system of signs, and then decipher the meaning. We all read ourselves and the world around us in order to glimpse what and where we are. We read to understand, or to begin to understand. "We cannot do but read. Reading, almost as much as breathing, is our essential function" (Manguel, 1996, pp. 6-7). I interpret Manguel as describing how the person, his own story, perceptions, and memories, interact with the written words. Further, we must consider how these factors, as well as factors such as time, impacts this process of interpretation of what the person has read. Rosenblatt (1968) suggests that through books, the reader can not only explore their own nature, but become open to new thoughts and feelings within themselves, perhaps acquire a clearer perspective or develop a sense of direction and aims.

The word "bibliotherapy" can be defined as the use of specific books that are selected on the basis of chosen topics, in an effort to help people solve problems. The word itself is derived from *biblio,* referring to books, and *therapy,* referring to a controlled and studied approach to therapy, using a specific method such as music in music therapy, art in art therapy, dance in dance therapy, and behaviour modification in behaviour therapy, to name just a few. The use of books as therapy can be traced back to the first libraries in Greece. The notion of using books as a way to encourage healing has been interpreted by various professional groups that include classical scholars, physicians, psychologists, social workers, nurses, parents, teachers, librarians and counsellors.

Perhaps one of the earliest references to reading books as therapy is in the early 1900s when a specific term was coined for the use of books to affect a change in a person's thinking or behaviour. Crothers (1916) discussed a technique he used to prescribe books to patients who needed help understanding their problems. He labelled this technique "bibliotherapy" (Crothers, 1916, p. 291). As well, bibliotherapy has been defined by Riordan and Wilson as, "guided reading of written materials in gaining understanding or solving problems relevant to a person's therapeutic needs" (1989, p. 506).

The application of bibliotherapy was initially limited to hospitals, where it was used as an adjunct to the library services provided to World War I veterans. By 1940, its use had spread to a variety of settings (Agnes, 1946). The term bibliotherapy has been used to describe practices from just suggesting books to read, to using the content as a therapeutic intervention by a trained professional. The current literature on bibliotherapy

tends to differ, depending on the orientation of the author, which makes it difficult to form a consistent, unified theory or explanation. Nonetheless, the literature does point to the advantages of reading in general.

In 1988, Strayhorn proposed using bibliotherapy to enhance various forms of thinking: nurturing others, dealing with disapproval, and dealing with teasing or criticism. This use of reading as a method to address one's emotional needs is one of the foundations of bibliotherapy. By reading stories in which the characters' feelings, problems, and emotional challenges are similar to their own, children and adults may discover ways to solve their own problems.

As the field grows, there has been some confusion over what bibliotherapy really is. Work within the last decade, at least within the Canadian context, has sought to understand the value of bibliotheraphy within the context of an actual academic organization. Joseph Gold (1990, 2002) founded The Association of Bibliotherapy of Canada, which later became ABAL. ABAL is an academic association whose members represent various disciplines and share interests in studying and promoting the application of literature as well as the processes of reading and writing as life enhancing resources. ABAL quotes Robert Oxlade's definition of bibliotherapy as follows:

> ... referring to the use of literature as a aid in therapy, particularly for people suffering from psychological trauma or mental illness. Bibliotherapy has rapidly evolved in scope and sophistication to become an area of interdisciplinary study and practice. It now links professionals from the world of language, literature and arts with educationalists, psychologists, and clinical therapists from a wide range of professional

> backgrounds and focus. It has extended from its original book-reading dialogue therapy to include therapeutic uses of writing. The medium also expanded from print to include audio-visual aspects of narrative through, for example, film and video. The common thread is the belief that we can all, in our different ways, contribute to or benefit from, reading and writing to enhance health, growth, healing and well-being (ABAL 2003).[1]

Joseph Gold is well known for his work in this area, particularly as the author of the books *Read for Your Life: Literature as a Life Support System* (1990) and *The Story Species: Our Life-Literature Connection* (2002). He is a professor of English and a clinical member of the American Association for Marriage and Family Therapy. His unique blend of knowledge and experience can be seen in his original and comprehensive approach to bibliotherapy. Gold explains how bibliotherapy can be used during the various stages of a person's life, and in response to specific stresses such as divorce and growing old. He describes the more common approaches to bibliotherapy, such as reading about one's illness or their life situation, or reading about a person or people, fiction or non-fiction, who have lived through a similar situation. He also describes other less commonly understood and utilized forms of bibliotherapy such as reading comedy to relieve negative emotions through laughter, or reading tragedy with an "it could be worse" response. Gold describes a unique, yet inspirational technique he uses in his clinical practice. He explains how he listens to a person's interpretation of a novel that both he and the client have read. He uses this interpretation, to better understand that person, the way the person interacts with the written material to formulate their

---

[1] ABAL 2003, *What is Bibliotherapy?* Available at: http://laurentian.ca/abal/biblio.htm

interpretations and the objectives they develop from this. By asking his clients to read a specific book, and then asking specific questions in an attempt to stimulate discussions about plot, character, theme and so forth, Gold reports gaining a better understanding of his clients through their comprehension and interpretations of what they have read.

Gold discusses how people keep homeostasis, (i.e. physical bodily balance). He also explains emotional and cognitive balance and the process of achieving cognitive balance as "the times when our thinking and feeling must be adjusted to return us to 'narrative equilibrium'" (p. 119). He further explains that the problem with balancing our views of events and experiences may be complicated by our wish to avoid painful thoughts or feelings. "The role of reading other stories in helping us maintain balance becomes clearer as we learn to create our own story with awareness" (p 124). Gold compares our writing or telling stories to the work of a weaver: "we are the weavers of a tapestry constructing a story as we sit at our loom" (p. 125). Gold questions how we can be weaving our stories, while at the same time living our lives, how we can go outside ourselves to see ourselves, and how we can be the director and the actor or the coach and the player at the same time. These questions remind me of similar dilemmas felt by the researcher doing phenomenological work, acting as researcher and participant at the same time in reporting the narratives of others, while reflecting and using one's own memories and experiences to understand the phenomenon under study.

Gold explains "Edit and change, review and we certainly must, there can be no doubt about that, if we are to make the shift to healthy functioning when the story gets stuck" (p.126). He explains how individuals are the stories that they weave and create. He cautions that if the story falters, the result may be confusion and even sickness.

Gold explains that the very positive aspect of literature is that it allows us to proceed through this "mind shift" process more safely without the physical or relational risk, while gaining an increased knowledge of ourselves. He points out however, that we cannot live entirely in books, as we must gather life experiences in order to make some sense out of what we read. This is important to remember as it stresses the need for a person's self-contribution to their interpretation and understanding of what they read. Gold concludes his thoughts on this process, by suggesting that the best device for removing oneself from one's story long enough to see it differently and to see what must be changed, is literature. Gold explains that the purpose of using fiction as a means of therapeutic intervention is to "move the reader's brain into language/narrative action" (2002, p. 136). He describes the process both cognitively and neurophysiologically and explains how reading fiction can be seen as a practice for reading one's own life. He uses the term "reading" to signify a form of self management that he describes as "an active and creative thought process achieved in the medium of language" (2002, p. 136). He explains that the fiction or poetry becomes incorporated into the reader's brain as a process of self-regulation and is "spliced" into the reader's prior experiences, store of tools, information and repertoire of language.

This explanation of reading, while evaluating and changing one's own story, particularly as a therapeutic exercise can be easily applied to mothers of children with special needs. I am reminded of a one-page narrative titled, *Welcome to Holland* (see Appendix B). It is written as a reflective piece about having a child with special needs. The story describes a person preparing to take a long trip to Italy. She learns the language, researches the country's foods, the museums, the scenic attractions and so

forth. She packs her bags with the appropriate clothing and boards a plane to Italy. However, upon landing, the flight attendant informs the passengers of their impending arrival and welcomes them to Holland. The traveler, who feels she is totally prepared for Italy, acknowledges that she knows nothing about Holland. She expresses her fear and disappointment. She describes her sadness and jealousy as she remains in Holland while others come and go from Italy – a place she describes as being "fast-paced and more exciting." She then describes how she realizes that while different from Italy, Holland probably has a lot to offer. Some parents of children with special needs find this narrative simplistic and even insulting, as it perhaps minimizes the deep emotions and turmoil involved in this tale. However, other parents find this same narrative comforting as it is comparable to expecting to deliver a "typical" child and finding out the child is "different." In a sense it is like the process of writing one's story; although one may start out with a lot of planning before writing begins, one can discover it does not always turn out as expected. This type of narrative may help the mother to move outside herself and rewrite her story. Perhaps this is why so many mothers need to tell and/or write their stories often with a burning desire to help others.

What I have discovered during my literature review, is very much in line with Joseph Gold's views. While reading his most recent book *Story Species* (2002), I found it to be informative, inspirational as well as validating. I realized that the processes of reading, writing and storytelling are entwined and often difficult to separate as entities on their own. The literature reflects an interdependency of sorts; reading leads to writing, which leads to reading one's writing aloud, which leads to discussion and storytelling, which then leads to more writing, both alone and in groups. Therefore, in this literature

review I include the literature on storytelling, narrative therapy, as well as writing groups and writing as therapy. I try to follow the delineations between topics as suggested in the headings, however, the natural overlap becomes apparent within the text.

Schlichter and Burke (1994) distinguish two types of bibliotherapy: clinical and developmental. Clinical bibliotherapy is described as therapy used by trained professionals as part of a comprehensive treatment. Developmental bibliotherapy is described as an approach used to anticipate issues before they may become a problem, for example, before a child starts school. In order for bibliotherapy to be effective, it requires more than just the recommendation of a certain book; the reading should be a part of a planned course of action and therapy that requires careful consideration and application. (Bibliotherapy, 1982) Bibliotherapy must be handled with great delicacy, and not every practitioner possesses the personality traits and characteristics necessary to be a successful facilitator in the process. A practitioner must also decide whether individual or group therapy would be best in a particular situation, or if some combination of the two would be preferable.

In a therapeutic context, bibliotherapy should include identification, modeling, problem solving, immunization, feeling and training (Gold, 1990), or identification, selection, presentation and follow up (Pardeck and Pardeck, 1993). Some therapists use bibliotherapy in conjunction with their individual, family or group therapy. The therapist may recommend appropriate reading to parents and/or teachers. Riordan and Wilson (1989), in a review of the literature on the effects of bibliotherapy, found that a majority of the studies show mixed results for the efficacy of bibliotherapy as a separate treatment for solving problems.

Gold (1990) suggests that there is a direct link between what readers feel about what they read, and how they feel about themselves, their relationships and their attitudes. It would be interesting to look at issues such as how mothers interpret and feel after reading about other mothers in similar situations and how their interpretations are related to their stage of mourning for example, denial, anger, guilt and so forth at the time of the reading for example, initially after diagnosis or years later.

Stanley (1999) suggests twenty common ways that bibliotherapy can provide comfort and promote growth and healing as follows:

> To cultivate aesthetic appreciation for intellectual stimulation; to gain a sense of accomplishment; as a stimulus to discussion; to reinforce feelings of normality; to enhance one's leisure life; to help ease boredom and loneliness; to learn practical skills; as a means of assessing values, attitudes and behaviour; to create an awareness that others have similar problems; to expand one's focus beyond oneself; to overcome resistance to change; to vicariously experience others' lives; to understand new ways to approach and think about problems; as a source of motivation, encouragement and inspiration; as escape and diversion; to alleviate a sense of futility; to connect or reconnect with the larger community; and to reinforce one's sense of self worth. (1999, pp. 26-38)

Stanley, similar to Gold, discusses different types of reading, self-help, non-fictional memoirs, non-fictional autobiographies, fictional memoirs and fictional autobiographies and novels – including comedy and tragedy.

Writing for Ourselves and for Others

In my review of the literature, I noticed that there was little to be found on the actual benefits of mothers writing. It is touched upon, yes, but there has been no definitive study that does more than just imply that writing is beneficial. Beck (1997), the author of *Breaking Point,* is a good example. In this book, she writes about the stories of women, women who chose to stay home and women who worked, women who were mothers and those who were not, women of all ages. That is, she reviews relevant issues such as the dilemmas and conflicts mothers face between working and/or staying home. She uses the stories women told her during interviews for her Ph.D. thesis, to illustrate her points. She discusses stories of women reaching their "breaking point" and even tells about her own "breaking point" when she found out she was pregnant with a child with Down syndrome. It is interesting to note that two years later Beck, had another book published, a more personal book called *Expecting Adam* (Beck, 1999), where she tells her story about having a son with Down syndrome. The style of writing differs considerably between her book describing her research and her personal story. The first was presented in a style geared at being more objective and professional. The second appeared to be more personal, honest, open and spiritual. Her personal book reveals a deep, emotional and vulnerable side, where she expresses her criticism of the professionals and the cold attitude she encountered. She used storytelling in her research and she told and wrote about her own personal story, illustrating a deep, perhaps subconscious, understanding of memory work and writing. But nowhere does she make the explicit connection between mothers of children with special needs (herself being one) and the therapeutic benefit of writing (*Expecting Adam*) or telling their story. There are no references to writing,

storytelling or narratives. In one of her later books, *Finding Your Own North Star: Claiming the Life You Were Meant to Live*, Beck (2001) describes her experiences of writing both her Ph.D. thesis and her memories at the same time. She describes her thesis as her "husband" and her written memories for her personal book as her "lover." I can certainly relate to her experiences as I write my thesis, while resisting my other project of putting together a collection of the narratives and other written work produced during this project.

My interest in mothers' writing comes out of the vast body of literature on the personal benefits of writing and my own experiences as a women, a mother, a mother of a child with special needs and a clinician, where I have experienced and observed the many benefits of writing. The act of writing can be accomplished in many ways (e.g. pencil, pen, computer, notepad, journal, etc.) and for many reasons (e.g. communication, organization, therapy, entertainment). Writing can be private or public and can take one of many forms for example, poetry, prose, letter, notes, lists, to name just a few.

Dias, Beer, Ledwell-Brown, Paré, and Pittenger (1992) refer to the process of "writing for ourselves", which can be described as a situation in which a person writes primarily for themselves, and knows that only they, or perhaps a few selected individuals, will read what is written. Two examples of this type of writing are a journal entry or a personal letter. According to Dias *et al.*, this type of writing is often considered easier for the writer to do, compared to a piece of writing that will be read by others. This is understandable, since once something is down on paper, it becomes permanent, with the paper and its contents becoming like a receipt that can be kept as a record and read and re-read at anytime. Just the knowledge that something may be read by another person

could be an inhibiting factor in the whole process, and that is why most journals are kept private and often discarded. Dias *et al.*, compare writing for oneself to speaking to a close friend. An example of writing for others is a letter of recommendation.

As cited in the introduction, the novelist E.M. Forster's famous saying, "How can I know what I think, 'til I see what I say," is an eloquent explanation of the common need for people to see their thoughts and words on paper, a process which can aid them to solve problems and find some clarity.

To explain the different types of writing, I refer to Britton, Burgess, Martin, McLeod, and Rosen (1975), who describe the process of writing to get things done as transactional writing - the kind of writing most often seen in the workplace or places of education, for example in memos and bulletins. This is also a type of writing used by mothers, for example, when they write grocery lists, notes to teachers, and to-do lists. The "communication book" is a tool often used between parents and teachers of children with special needs. This book has been described as helpful, but also as hurtful and has been well used, but often abused. Shilts (1999), in her autobiography, describes her reactions both positive and negative, to notes in her sons' communication books. The communication book is a term and concept used by most teachers and other educators, working with students with special needs, to describe a vehicle for written communication between home and school about a specific child. The style that is used in these communication books consist of forms, charts and/or diary. The purpose of these communication vehicles may be used to accomplish different objectives such as to describe behaviours good or bad, to provide information such as to send in a milk carton for an art project, or to provide written or pictorial narratives of the day to enhance

conversation at home. I was not able to trace the exact origin of the communication book. However, it is frequently described in mother's autobiographies and parenting books on raising a child with special needs. On some websites for parents, the values and pitfalls of communication books are described as follows:

> For greatest effectiveness, teachers are encouraged to work with parents to support students with AD/HD. For example, a communication book signed by parents can be said to ensure that parents are aware of issues that arise in class and teachers are aware of issues that arise at home. Both should ensure that positive messages are included frequently, as parents and teachers can grow discouraged when negative comments dominate communication (Government of British Columbia Ministry of Education web site, www.bced.gov.bc.ca/specialed/adhd/managed.htm).
>
> For parents that can't get into the school regularly, the communication book, or planner, that the student brings home each night is key. The book or planner can be used to note changes at home, sickness or events that may impact on school work. In return, the classroom staff can share the day's events, the student's achievement or their concerns. A communication book will not cover all situations and it is important that parents also call or contact staff when a concern arises. Negative comments, when written on paper, can be hurtful and lead to misunderstandings (Ontario Association for Families of Children with Communications Disorders web site, www.oafccd.com/factshee/fact18.htm).

The two definitions quoted describe the process well. One point that was consistently noted was to try to increase positive notations and avoid negative, hurtful

comments. This was consistent with the concerns and complaints raised in a number of the autobiographies and memories written by mothers regarding the potential negativity of this potentially excellent tool. This tool is a good example of the way that writing can facilitate the sharing of information. Facilitation of the child's education and development and the enhancement of parent-teacher communication and relationships may more likely be realized using this system appropriately.

Britton (1975) describes expressive writing as a form of writing often used in diaries and journals, the kind of writing people do for themselves. It is in this type of writing that the writer's voice is clear, as are the writer's feelings and attitudes. Dias *et al*, (1992) explain that expressive writing encourages us to express our feelings and explore new ideas. They suggest that this is the type of writing found in diaries, journals, field notes, initial observations, and written records. They discuss "journal keepers" as all types of people who use journals as a way to reflect on their relationship with the world and to evaluate and better understand the implications of those relationships. "The journal keeper knows that the chaos of life becomes meaningful as we reflect upon it, articulate and shape it with language, or interpret it through art" (Dias *et al.*, 1992, p.26).

A third type of writing proposed by Britton is poetic writing. This is when language is being used as a form of art.

Dias *et al.*, (1992) suggest that the boundaries between these three types of writing - transactional, expressive and poetic - are not clearly delineated and tend to "merge and overlap." Whether writing for oneself or for others, the shelves in the libraries and bookstores are filled with a huge number of books and magazines on the benefits of writing for profit or for personal growth and healing, with pages and pages of

"how to" lists. The authors come from a wide range of personal and professional expertise: psychotherapy, marital and family therapy, journalism, English literature, education, from elementary to university, psychology, social work, anthropology, artists and the creative art therapies to name a few. The following is a partial list of some of these self help/how to writing books. *Journal to the Self: Twenty-Two Paths to Personal Growth*, Adams (1990), *Journaling for Joy: Writing your way to Personal Growth and Freedom*, Chapman (1991), *Writing Down the Bones: Freeing the Writer Within*, Goldberg (1986), *Writing Your Authentic Self*, Guarino (1999), and *The Power of Personal Storytelling*, Maguire (1998).

Writing as Therapy

In the same way that bibliotherapy is the use of "guided reading of written materials in gaining understanding or solving problems relevant to a person's therapeutic needs," (Riordan and Wilson 1989), therapeutic writing can be seen as a means of guided writing to enable a person to gain insight into understanding a problem and/or developing and using effective skills to solve those problems. In this way, the process of writing takes on the therapeutic qualities of fostering mental health and emotional competence. (Bracher 1999; Chapman 1991; Fitzpatrick 1998; Freeman, Epston and Lobovitz, 1997; Keen 1990; Kindig 1997).

Researchers agree that writing promotes both critical thinking and learning (Britton *et al.*, 1975; Bruner, 1975; Emig 1977; Herrington, 1981; Knoblauch and Brannon 1983; Odell (1980); Parker and Goodkin, 1987.) As previously mentioned, writing has often been described as a method to foster clarity of thought. When one's

thinking is clearer, one is more likely to see a situation and its related emotions more clearly and deal with it and problem solve more effectively. This is a particularly important component of adjusting to and dealing with mothering a child with special needs. A popular method of writing commonly used to develop insight is journal writing. Ira Progoff, a psychotherapist and renowned proponent of this method, believes that this personalized style of writing enables individuals to gain perspective on major periods of their lives, identifying inner strengths, new possibilities, and discovering resources and talents within themselves (Progoff, 1992). Adams (1990) in her book *Journal to the Self* describes her "smorgasbord" journal approach. She describes journal therapy as the use of the journal or diary to "facilitate holistic mental health and self reliance" (Adams 1990, p. xiii). She describes the history of journal writings as being traced as far back as the 10th century Japan where ladies of the Heian court reportedly wrote their reflections about life and love in their "pillow books." She credits Dr. Ira Progoff as being the leader of journal therapy since 1966. McGihon (1996) states that narrative or journal writing can help individuals pinpoint the areas of conflict in their lives and clarify complicated issues. Nelson (1994) writes about Journal Writing as therapy in his book *Writing and Being: Taking Back our Lives through the Power of Language*. He suggests that our words are born in our hearts and find their way to our heads. He recommends that the place to begin is with our feelings. "As we take back our feelings, value and validate them, acknowledge and explore them, we experience a new creativity and power in our words and a new vitality in our lives." (Nelson 1994, p. 37) Nelson explains that personal writing in our journals is the "heart of all writing." He explains that "there, our words become tools for our psychological, intellectual, and spiritual growth."(Nelson 1994, p. 40) Nelson

believes that "by telling our stories – first , to ourselves in Journals and then – if possible, to others in public writing – we can heal ourselves." (Nelson 1994, p.106) Klein (1998) suggests that the best way to deal with stress may be to write about it. In a study of college students, Klein found that daily writing was correlated with working memory – which he describes as a cognitive skill essential to problem solving, comprehension, and reasoning. In an examination of the results of a creative writing program in which participants shared their own stories and responded to their peers, Chandler (1999) found that the writing intervention focused on the building of one's self-esteem, and aspects of self-efficacy that resulted in an increased sense of well-being. Tryssenaar (1995) describes the use of interactive journals to foster and develop reflective skills, and found positive changes in attitude associated with new knowledge and experiences.

There are a variety of ways to use writing as therapy, and journal and letter writing are examples of two very effective methods. Expressing feelings and thoughts in a letter has the potential to change the letter writer, according to Vance (1998). She suggests that this potential to change feelings and thoughts is possible even if the letter is never sent. She further suggests that the mere action of writing as a form of expression and release, has the ability to increase the writer's recognition that he or she can behave differently. Writing a draft of a letter can create a temporary responsibility shift, similar in its results to the exploratory quality in children's pretending. Exploration works best when trials are felt to be just that, an exercise that does not "really" count. This is when the assignment to write a letter often is carried out only when the writer is reminded that she does not have to send it, that she doesn't even have to write a letter of outstanding

quality. The important element to keep in mind about writing, be it in a letter or a journal, is that the person writes for the sake of the writing itself, without having to think about the quality or the quantity of the work. Once the fear of being judged is lifted, a person begins to truly perceive that they have the freedom to explore their thoughts and the expression of those thoughts.

Once it is written and revised, a letter often feels "right" for the writer. It becomes a true expression of what a person is feeling. Previously formed barriers tend to melt away. The process of composing the letter - going through the stages to create impact, throwing out debris, working through feelings and getting at the truth - is so compelling and even empowering, that only in rare cases does the letter not get sent. And although there may be elements of fear in sending the letter, the level of that fear is generally manageable. Epston (1994) suggests that words written in a letter have a permanency that words in a conversation do not have. He further suggests this permanency may have lasting therapeutic effects. Adams (1990) suggests that unsent letters are marvellous tools for the three C's, which he explains are catharsis, completion and clarity.

Freedman and Combs (1996) used letter writing as a component of their therapy. They report that letter writing serves three main purposes: (1) to summarize and recap their meetings, (2) to extend ideas or stories that were initiated during therapy conversations, and (3) to include people, (i.e., family members who were not present at the sessions). Mickelson (2000) in her study of mothers of boys with severe behavioural problems, used letters to communicate with the participants in her study, and as a feedback regarding their storytelling during interviews.

Aronie (1998) compares our written stories to yesterday's soup, "rich, layered, filling: it's a meal. Soup needs time" (1998, p.14). She explains that our stories are carried around in our bodies and are embedded in our souls our whole lives. She suggests that when it is time to write, most of our work has already been done. Whether the thinking and creating is done consciously or unconsciously, the pieces have "been cooking." She describes the writing process as follows:

> You write, you add, you tighten, you leave it alone, you think, you take a whack, you call your mother, you fix, you sharpen, you print, you read, you hate it, you love it, you hate it, you give it time, you come back, and you begin again (Aronie 1998, p.14).

Aronie so naturally describes the process of writing just as it is. It is during this process that the image of soup emerges, where writing is seen akin to cooking, where feelings and emotions are rising. The writer is dealing with these thoughts and feelings, feeling them again or feeling them differently, suffering again or perhaps finding resolution, or in the case of suffering, finding relief.

Aronie relates her stories of pain in childhood and explains, "I, like others, learned early what pain, humiliation, exclusion, cruelty felt like. I memorized it and I held it as precious cargo that now infuses my messages" (Aronie 1998, p. 21). This need to infuse one's message is what often helps people write and deal with their pain. This is particularly true of mothers raising children with special needs, who simultaneously suffer their own pain and exclusion, while they suffer the pain and exclusion experienced by their child. Writing about these feelings with the hope of passing on a message to others can often be very powerful and therapeutic.

> We pass for who we are, especially when we put it in writing. The tone you take in your memoir will tell more about you than the best photographer can capture. One of the things that still amazes me about writing is how much I learn about myself when I read what I write. (Stanek, 1996, p. 87)

Stanek's comments strongly resemble Forster's. Once again, this stresses the importance of seeing our thoughts in our written words. Gabriele Lusser Rico (1994) suggests that even the smallest amount of writing has significant impact on one's life, and over time, allows us to gain meaning and perceive patterns in our lives.

In her paper *The Heart of the Matter: Language, Feeling, Stories, Healing*, Rico talks of the need for people to tell their stories, how it "reflects the basic human need to story our lives. Most of us must actually learn how to make use of this innate propensity" (p. 201).

Capacchione (2000) in her book titled *The Creative Journal for Parents: A Guide to Unlocking your Natural Parenting Wisdom* discusses the therapeutic and educational value of various forms of Journaling. Her book describes 44 exercises, using writing, drawing and collage making, to bring out an individual's "unique style of parenting." Capacchione explains that her own use of drawing and writing in her journal was a major component of her successful healing after an emotional and physical breakdown. She had previously been an educational consultant and she subsequently delved into a new career in art therapy.

Capacchione suggests that journal keeping can be an immensely helpful way to become more thoughtful and aware of the way a parent is parenting their child, by sorting through one's values, questions, observations and needs.

As helpful as writing seems to be to one's emotional development and stability, critical thinking, communicating and the organizing of oneself, it is a process that is often avoided. Keyes (1995), in his book titled *The Courage to Write*, describes writing as a courageous act. Although written mainly for a professional or aspiring professional audience of writers, Keyes vividly describes the fears associated with the process and act of writing, as well as self-judgment of one's perceived ability and work. He offers suggestions on how to work effectively and how to attempt to overcome these fears of producing written work. This may be related to what Gage (1986) eloquently describes as a superstitious belief that "there is a right and a wrong way to write." (p. 17) Dias *et al.*, (1992) describe the process of writer's block as sitting down in front of a blank piece of paper or computer screen and giving up with the promise to try again later. They suggest that this dilemma is often the result of a "reluctance to put anything that seems less than perfect on paper" (p. 93). They further suggest that "writers have strong internal monitors that censor ideas, word choices and sentence structures." They caution that the too often used phrase "think before you write," is in contradiction with our knowledge that the process involved in writing and even the product actually assists in thinking.

Butler (1992) explains that people of all ages "from children to the elderly find value in recovering and recalling memories and expressing their ideas in talking about prompts such as portraits, photographs, time lines, charts, etc." Butler clearly expresses the notion that "there is no doubt that the self is everyone's favourite topic of

conversation." (p. 33). For some mothers, their favourite or most frequent topic of conversation is their child. This appears to be even more frequent and apparent in the oral exchanges and written works of mothers of children with special needs.

Larson (1985) questioned the role of emotions in writing and suggested that the writer's task is to "assimilate facts and ideas into some form of lucid and compelling order to shape an intelligent organization of thought on page" (p.19). Larson discusses that the processes of prewriting, problem solving, attending to audience and editing are based on a presupposition that the writer is able to use controlled and rational thought. He suggests therefore that emotions would appear to be an important element for successful writing. Larson also suggests that emotions, be they anger, desire or excitement, are intrinsic to motivation and may be responsible for transforming mechanical texts into more "engaging prose" (p.20). Emotions may be disruptive or facilitative to successful writing. Nelson (1994) writes about writing as "a test for intellectual, psychological, and spiritual growth" (p.8). She suggests, however, that too often in school we study language and writing in isolation without considering the person who is speaking or writing about their feelings and emotions and without the context, such as what happens to them. She suggests that studying writing in isolation is "language without a heart."

Rainer (1997) suggests that "reminiscence", a phenomenon she quoted Aristotle as explaining to be a higher order function that is exclusive to humans, is necessary to successfully write memoirs. This, she suggests, is the opposite of straining to remember. The questions of where productive "reminiscing" ends, and "useless longing" begins, I believe, is in some ways consistent with the differences between normal feelings of mourning (i.e., denial, anger, guilt, and pathological denial, anger or guilt), and. being

stuck in a phase. Further, the whole issue of memories, real or fabricated, and the role of emotion and perception are essential to our understanding of memory and memory work. (Greenberg 2002)

Storytelling

It is difficult to separate writing for oneself as a type of story- telling in and of itself. It is for that reason that I include storytelling in this review. The telling of stories has a central place in human cultures throughout the world (Siegel, 1999). From early on, in fact, from the time they can speak, children narrate their lives as they begin to tell others about the sequence of events and daily experiences. Siegel questions what it is that is so special about stories and why as a species we are so consumed by the process of telling and listening to stories.

There is a relationship between writing and storytelling that is sometimes hard to separate. After reading aloud what one has written, a dialogue can ensue, often in the form of additional storytelling, sometimes by the writer, and sometimes by the listeners. This is when the line between writing a story and telling a story becomes blurred and less defined. This section addresses storytelling. When reviewing the literature, it's important to tease out and understand the different forms of storytelling, such as storytelling as entertainment compared to storytelling as therapy.

David Thomas (1995), in his general introduction to selected aspects of an approach to studying teachers and teaching, discusses using various forms of narrative as tools to identify perspectives on life, work and career. He stresses the importance of narrative and encourages us to recognize the narrative's long history as an ancient form

of communication, going as far back as pre-literate, oral tradition. Storytelling has crossed over cultures and over generations. Thomas states that the narrative has been credited with meeting profound needs within the human psyche, "the need to tell and hear stories" (Thomas, 1995, p.3). He states that narratives make up the devices for communicating, interpreting and providing meaning to the experiences we encounter.

Thomas discusses the many facets of stories – that is choices, and emphasis with regards to plots, motivations, characters and themes. He explains that our culture tries to distinguish between fiction and non-fiction, but he further suggests that it is likely that in most non-fiction discourses, there is a story fighting to get out. People have many positive statements about the impact of writing, such as the idea that telling one's story can confirm that it happened, can validate and even reassure the writer. It can empower the person. Writing, then, makes it real. Reading one's own writing is an important aspect of writing therapy. When reading aloud, one can hear oneself. Often when people share similar stories and/or issues, it becomes, in a sense, a method of validity. Therefore, oral storytelling can also be an effective means of expressing oneself, as well as being very therapeutic. Maguire (1998) describes personal storytelling as a mouth-to-ear transmission of memories shaped by our intelligence, imagination and spirit.
In Maguire's book he refers to the performance angle of oral storytelling and encourages the drama of it all. Nonetheless, he says that the feeling of telling a personal story begins deep inside with the "thrilling nerve tingling, marginally self-affirming recognition that we have in fact experienced something worth telling" (p. 9). In reading one's written story aloud, those listening to the story witness the tones, the gestures, the facial expressions and the rhythms that Maguire describes.

Maguire suggests that storytelling adds more meaning to our lives, connects us with others, fosters our creativity, enriches our humour, facilitates the development of courage and confidence and helps us to make our lives more memorable. He suggests that telling our own story can be very healing while helping us to validate those experiences that we tend to reject. By changing our negative, painful or chaotic experiences into stories, we begin to take responsibility for them so that they can be used constructively in our lives. Psychotherapists give their clients time, space and the encouragement they need to articulate what has happened in their lives because the process of telling their story is very instrumental in increasing their self respect and sense of integrity. Outside the realm of therapy, a similar kind of positive emotional change occurs when we share stories of difficult, embarrassing or guilt-ridden experiences – like going through a divorce or growing up overweight.

Stanley (1999), when discussing reading of fiction as a therapy, suggests we remember that even though the story the writer shares, did not actually occur, this does not mean what is written is not true. The same can be said for exaggerated stories or personal perceptions and memories of events.

Atkinson (1998), in identifying the importance of storytelling, explains that "the pattern of storytelling actually forms the base for the plot of a story and not only aids the storyteller in remembering the elements of a story, but also keeps the story on the course that it is meant to be on" (1998, p.2). Atkinson adds that, "the basic pattern of conflict followed by resolution or crisis, followed by victory, is a way that stories continually remind us that difficulties can be overcome." (1998, p.2) Atkinson (1998) has suggested that the telling of a life-story keeps the presentation in the first person and that through

these stories, we gain content and meaning. An oral history usually focuses on a specific aspect of a person's life. The story brings order and meaning to the life of the teller, as well as for the listener. Atkinson suggests that we are continually telling episodes and passages of our own life stories, a process that enables us to be heard, recognized and acknowledged by others, and includes aspects of our life and experiences that we want to pass on to others. Storytelling highlights the most important influences, experiences, circumstances, issues and themes, and in the telling, may help us believe that our life stories make a difference.

In describing the history of storytelling from generation to generation, Atkinson explains how these stories carry enduring values and lessons about life. He believes that traditional stories follow patterns that are both "timeless and universal" (1998, p.2). The events of our lives are made up of beginnings, conflicts and resolutions, with many repetitions of this pattern. He states that, "our lives and our stories about them, thus unfold according to an innate psychological blueprint, just as our biological development is governed by the genome, a genetic blueprint embedded within the species" (p. 3). Atkinson points out the "everyone has a story, even many, to tell about their lives and that they are indeed important stories" (p. 3). He further suggests that by sharing these stories we create vital links with the other participants in the exchange. In the process of telling our life stories, we share important personal truths.

When discussing life stories as a research tool, Atkinson (1998) points out that the life story narrative can be an experience which is as much a value to the person telling the story, as it is to the researcher gathering the data. He explains this to be true because a life story narrative includes the experiences that we want to pass on about ourselves. Our

story tends to highlight the most significant "influences, experiences, circumstances, issues, themes and lessons" of our lifetime (p. 7). Atkinson credits cognitive psychologist Jerome Bruner, for illustrating that personal meaning is constructed during the making and telling of an individual's narrative. Bruner's theories suggest that an individual's life experiences take the form of the narratives that we use to tell them. He theorized that one's stories are one's way of organizing, interpreting and creating meaning out of our experiences, while still keeping a sense of continuity. Bruner (1990) further suggests that experiences and situations that cause distress to an individual "demand" a story and that using a narrative structure to deal with an emotionally charged event is an effective way of dealing with these events.

Atkinson reports that we use the process of putting our life together in the form of a story to help us become fully aware of our lives. Telling our story gives us an opportunity to be recognized and acknowledged by others. These aspects of storytelling may be even more important to a mother of a child with special needs, where the need to be heard and to be validated becomes more and more important with each struggle, challenge and attempt by others to assign blame. Atkinson states that "story makes the implicit explicit, the hidden seen, the unformed formed and the confusing clear" (1998, p.7).

Fitzpatrick (1998) states that stories "ground us in the traditional, most ancient ways of nurturing emotional wisdom: family, culture, spiritual roots" (p.5). She captures the true sense of storytelling in her explanation that when we hear the words "once upon a time", this brings us to a way of experiencing life that is out of the ordinary and at the same time very much like our own. She suggests that real stories, imagined ones, or a

combination of the two allow us to enter a number of possible activities (i.e., dream or imagine or identify and relate). She strongly suggests that nothing is more true than a story.

Siegel (1999) suggests that each of us has a large number of anecdotes that serve to illustrate particular emotional feelings or events from our past. He, like others, uses the analogy of weaving a tapestry of memories into a story as we imagine the details so as to create our story which is motivated by our past events, as well as by our present need to engage our listener. Siegel suggests that as we change as individuals over time, our narratives also alter to reflect these changes, so much the nature of human life and relationships.

Haaken (1998) suggests that stories are "important terms of interpersonal exchange, conveying information about internal concerns and desires even as they stimulate states of mind in the listener" (p. 54). Haaken suggests that the telling of a story "inscribes its format in memory, sometimes replacing previous versions of the tale" (p. 59).

Freeman, Epston and Lobovitz (1997), explain that people tell stories in their internal dialogue and in other social communications about themselves and others. "Personal and relational stories come in many forms; some are tragic, comic or romantic, others are mundane or repetitive. Some are startling. Some inspire, others accuse or degrade." (1997, p.47) Freeman *et al.*, explain that, "While no story can hope to completely capture the complexity of lived experience, what we emphasize or omit has real effects on the teller or the listener" (1997, p.47). Atkinson suggests that:

> Perhaps one of the most important uses of the life story interview is for the therapeutic effects it can have. Telling a life story is not meant to be therapeutic, but it can often help the person clarify or understand something that might not have been understood as much as possible before the telling. (p. 12)

Narrative Therapy

The telling of stories oral and/or written is often referred to as narratives (i.e., telling of a story). This is the basis of narrative therapy. Narrative therapy includes telling and retelling one's story.

While writing this thesis, I was continually developing my skills as a psychologist. While reading, I saw more and more how the telling of one's story is used for evaluation and treatment of psychological and psychiatric disorders, and how using and changing stories are an essential part of the healing process. I realized that in a sense, psychotherapy is telling or writing one's story, while cognitive behavioural therapy is rewriting one's story. The word narrative therapy is used in many sections of this paper to describe stories written or oral. Perhaps, narrative therapy could be described as telling/writing one's story and then revising/rewriting their story. Narratives are used in many contexts-research and therapy being two major ones. This section describes how narrative therapy is based on the premise that humans live their lives according to stories that reflect the meaning that people attribute to the events and experiences they live daily (Nylund 2000; Freedman and Combs 1996; White 1991; Freeman, Epson and Lobovitz., 1997). Stories are believed to describe and shape the lives of people. Therapists and

researchers believe that individuals and families become "bogged down in dominant stories that disqualify, limit, or disempowered them" (Nylund 2000, p.46). Narrative therapists attempt to change "problem-saturated "stories by trying to separate the problem from the person and by writing stories of skill, resiliency and ability. Nylund (2000) finds the narrative metaphor invaluable in therapy. He explains that a narrative view of the person suggests to the clients and to the therapist that "everybody lives a multistory-ied life" (Nylund, 2000, p.47). Siegal (1999) suggests that the narrative process attempts to make sense of the world and of one's own mind and its various states.

Narrative explanation and narrative meaning consist of significance, value, and intention. These three dimensions of meaning relate to the structure of time and help a writer structure plots where both the explanation and meaning themselves may be said to include a component of time structure. Furthermore, this structure helps portray a sense of purpose on the writing as one deals with various data related to time and then places them in time (i.e., past, present, or future oriented parts of the narrative). A part of the difficulty encountered in writing narrative, is in finding ways to understand and portray the complexity of the continuing stories being told and retold during the inquiry. We re-story earlier experiences as we reflect on later experiences so the stories as well as their meaning may move and change over time. When being involved in a reflective research process, our stories are often restored and changed as we "give back" to each other creative ways of seeing our stories. The following is an illustration of the process: I tell you a story. You tell me what you heard and what it meant to you. I hadn't thought of it that way, I am transformed in some important way, and I tell the story differently the next

time I encounter an interested listener. Connelly and Clandinin (1990) explained how they realized that they needed to tell their stories.

> Scribes we were not; story tellers and story livers we were. And in our storytelling, the stories of our participants merged with our own to create new stories, ones that we have labeled collaborative stories. The thing finally written on paper (or, perhaps on film, tape, or canvas), the research paper or book, is a collaborative document; a mutually constructed story created out of the lives of both researcher and participant. (Connelly and Clandinin 1990, p.12)

Freedman and Combs (1996) explain that using the narrative metaphor led them to think about people's lives as stories and to work with people, particularly in family therapy, to experience their life stories in ways that are meaningful and fulfilling. They explain their interest and attractions to the work of Michael White. White (1991) explained his view well in the following quote: "The narrative metaphor proposed that persons live their lives by stories - that these stories are shaping of life, and that they have real, not imagined, effects" and "that these stories provide the structure of life." (p.28) White (1991) is encouraging in his belief that these are always "sparkling events" which oppose the "problem -saturated narratives."

Freeman *et al.* (1997) explain that people tell stories in their internal dialogue and in other social communication about themselves and others. "Personal and relational stories come in many forms: some are tragic, comic or romantic, others are mundane or repetitive. Some are startling. Some inspire, others accuse or degrade" (1997, p.47). Freeman *et al.*, (1997) explained that "while no story can hope to completely capture the

complexity of lived experience, what we emphasize or omit has real effects on the teller or the listener" (1997, p.47).

Understanding the effects of telling stories on both the speakers/writers and then listener/reader may help one to understanding the value of support groups.

Support Groups

Seligman and Darling (1997) suggest that parent support groups have been effective in meeting the "information and support needs" of parents who have children with special needs (p. 54). They also suggest that professionals can make parents aware of opportunities for "long-distance" support through e-mail networks, the pen pal column of *Exceptional Parent* magazine and national support groups. Therefore, implicitly at least, writing and storytelling are suggested as therapeutic means. However, their value has not been evaluated in any formal way. Seligman and Darling write about "educative counseling" which they describe as "concrete'' information and guidance, and how this type of intervention is needed at all stages of the child's development, regardless of whether the child's condition stabilizes, worsens or improves. They refer to Laborde and Seligman's (1991) proposed model of three distinct counseling inventions: educative, personal advocacy and facilitative counseling. Seligman and Darling (1997) discuss these groups with regards to format, purpose and whether the groups are therapeutic or educational. They go on to explain that some may argue that educational groups are also therapeutic. Seligman and Darling (1997) discuss how the *Exceptional Parent* magazine prints success stories about parents and by parents who have actively challenged the

authority of professionals. The authors suggest that stories such as these may inspire other parents to pursue more services or better services for their children.

Seligman and Darling also discuss more formalized programs in both assertiveness and advocacy training. As well, they explain that a number of books and manuals have been written and published familiarizing parents with their legal rights and with effective means of interacting with professionals. Many different kinds of support groups were discussed. However, as in my own literature review, they made no reference to any writing groups and although means of obtaining information through internet sites and support groups were alluded to, no bibliotherapy groups were reviewed.

Marsh (1994) edited a book titled *From the Heart: On Being the Mother of a Child with Special Needs* which was a product of a support group process offered by the Parents in Partnership (PIP) project, a project established for mothers of children with special needs. The stories were told by the mothers participating in a support group and were transcribed and edited at a later date. Some were written as reflective thoughts of various lived experiences. Project P.I.P. was developed to support parents and enlighten professionals about the necessity of forming partnerships. This was set up initially as a three year project. Although the exact nature and underlying objectives of the group were not clearly described in this book, it appears that this project was more of a clinical/advocacy type project, without a strong research basis. In the acknowledgement section of her book, Marsh explains that every group meeting began with each mother sharing current thoughts on family, work or other pertinent issues. She states that, "The storytelling that resulted was truly touching." (p. ix) According to Marsh, she believes that a strong support between members resulted from this exercise. She reports that all the

mothers felt that hearing the stories of other mothers in similar situations was "affirming" and appeared to offer them support and strength in dealing with their own issues. However, she was not clear on how she interpreted her final results. All comments appeared to be personal anecdotes on the part of the leaders of the group. A physician, Dr. R. Marion, wrote the forward to this collection of stories. He explains the need for physicians to learn what their patients and the parents of their patients need. He explains how this collection of stories opened his eyes. The book contains transcripts of the stories with few summarizing comments about the process and the comments about the process were mainly in the acknowledgements. There was one mention of the mothers need "to be heard." (1994, p.1)

Fitzpatrick (1998) in her book *Once upon a Family: Read-Aloud Stories and Activities that Nurture Healthy Kids*, suggests organizing a "story-sharing group" (p. 245). She suggests that this type of group can be profoundly nurturing. She warns that this type of group is not aimed at "mutual analysis", like group therapy, but rather offers an opportunity to join with others and create "a space apart" where the group members can allow the stories to touch their hearts. Her suggestions for starting a group include inviting friends and advertising on community bulletin boards. She suggests keeping the membership between four and ten members, setting a regular meeting date, finding a comfortable meeting place and finding a structure for the group that suits all the members. She appears to be trying to keep the art of storytelling within families alive.

Chapter Summary

In this literature review, I have highlighted many important aspects of reading, writing and storytelling as well as the way these activities are so closely interrelated, intertwined and necessary for each other. At the same time, I tried to identify the many delicate issues and needs of mothers who are parenting children with special needs. Finally, I tried to link these issues and techniques in an effort to demonstrate the need for and benefits of reading, writing and storytelling to the problem solving and emotional resolution processes that are necessary for this special group of individuals. Although there is literature on writing groups, and there is literature on support groups for mothers, I have not come across any literature that discusses writing groups for mothers in particular, or more specifically, for mothers of children with special needs. Nor, have I seen literature discussing narrative therapy and bibliotherapy as intervention for this particular group. Nonetheless, much of what has been written with regards to the use of writing groups to formulate ideas, bring up memories, and solve problems can be extended to all writing groups in general, including any which would be for mothers of children with special needs.

Chapter 4: Methodology

In this chapter I describe the methodological framework for this study of mothers of children with special needs and provide an outline of the ways in which, practically, I went about working with these women. I start by locating the work within a qualitative research paradigm. Following from this I look at how the work is informed by memory work and storytelling. My study is organized around the use of writing groups, an area that draws on the literature on memory work, focus groups and, of course, writing in a group setting. Essentially, I organized a writing group which was comprised of a group of mothers who were looking back while engaging in autobiography and other writing.

A Case of Qualitative Research

This study draws on phenomenological approaches to research. I was interested in the phenomenon of the experiences of mothers of children with special needs and the ways in which writing about these experiences might provide a strategy for assistance to them in and of itself. Van Manen (1990) explains phenomenology, in a broad sense, as a philosophy or a theory of the unique. We need to be reminded that in our desire to find out what is effective systematic intervention from an experimental research point of view, we tend to forget that the change we aim for may have different significance for different persons. Van Manen describes and discusses educational research and the tendency to "pulverize" life into minute abstractive fragments that are of little use to practitioners. Hermeneutic phenomenology research is a fundamental writing activity and may be seen as a dynamic interplay among six research activities as follows:

1. Turning to a phenomenon that seriously interests us and commits us to the world.
2. Investigating experiences as we live it rather than as we conceptualize it.
3. Reflecting on the themes that characterize the phenomenon.
4. Describing the phenomenon through the art of writing and re-writing.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon.
6. Balancing the research context by considering parts and wholes.

In a sense I was studying the process of writing and rewriting, at least in part, using the process of writing and rewriting. This type of research introduced me not only to a whole new set of methods but to a new language as well. Guba and Lincoln (1989) reject the usage of the term "generalization." They argue that this term given up as a goal of inquiry, is being replaced by "transferability." Like other qualitative methods, narrative relies on criteria other than validity, reliability, and generalizability. Guba and Lincoln further state that narratives are not adequately written according to a model of cause and effect, but according to the explanations from the overall narrative. I believe that few studies can successfully make cause and effect statements, as serious manipulation of the variables would be required, if this was even possible and ethical in human research. Even in quantitative studies, researchers can only state that a correlation exists, unless the area of study is investigated in a laboratory where all variables are controlled for. How could that possibly be carried out when studying human perceptions, emotions and memories? Imagine bringing mothers into laboratories for prolonged periods of time and telling them to think this way, remember only certain details, sit here and smile now, while the researcher is busily counting and recording. Although these type of studies have their place of importance, let's say when a particular drug is being studied to find out if it kills a certain type of bacteria, I don't believe that they

can successfully be used to understand the feelings, the perceptions of physical and psychological symptoms, and the emotions that an individual encounters with regards to taking the medication or the emotional impact of a disease that requires taking medication. Van Manen discusses that unfortunately, this presents a dilemma in the writing, because one needs to get down to concrete experiential detail. He suggests that trying to adjudicate between the whole and the detail at each moment of the writing, is a difficult task for the writer of narrative. To illustrate this, I chose to discuss a wonderful narrative written by O'Reilley-Scanlon (1995). I was taken by O'Reilley-Scanlon's description and comparisons of a qualitative and a quantitative researcher's observations and analysis of Van Gogh's painting. The comparison of the differences between counting strokes per minute, to truly studying the painter and his work was so revealing. I smiled as I read this fictional tale. I began to think of how equally ridiculous it would be to study mothers of children with special needs by counting how many times they smiled at their child in a five minute period, or how many tears they shed when they received the diagnosis.

Janesick (1994) uses "dance" as a way of describing qualitative research. She compares the qualitative researcher to an artist, explaining that at various stages in the design process, the researcher is situating and contextualizing the research project within the shared experience of the researcher and the participants in the study. The qualitative researcher as the "designer" of the research project recognizes the potential of design. Janesick suggests that the design serves as a foundation for the understanding of the participants' worlds and the meaning of experiences that are shared by the researcher and the participants in a given social context.

Janesick suggests that qualitative research design begins with a question. The researcher designs the study with a focus on real people and with the intention of living in the social setting of interest over a period of time. The objective is to understand the true meaning of the participants' lives in their own terms. Janesick describes her study on deaf culture in Washington, D.C. to illustrate this process. (Janesick, 1994)

Miller and Crabtree (1994) begin their chapter on "clinical research" by describing the story of a dying 32 year old woman, whose sadness grew with the conversations she had with clinicians and with researchers. They discuss the walls that are built between patient and clinicians, between patients and researchers, between qualitative and quantitative researchers and between academy and practice. They report that "patients and clinicians have usually been left out of research conversations" (p. 340). They discuss "translation" and "conversation" at these walls (i.e., between clinician and researcher) (p. 340), as well as how then to "tell the stories" (p. 348). This highlights the need for the patient, the clinician, and the researcher to work together - an exercise which would have beneficial implications in research involving mothers of children with special needs.

Featherstone (1999) in her extensive literature review titled *Taking Mothering Seriously: the Implications for Child Protection*, explores the increase in women and mothers "writing, as well as being written about" (p. 43). She stresses the importance of professionals beginning to listen to and read mother's stories to better understand the complexities of the issues. This topic is more extensively dealt with in the Mothering chapter of this study. Featherstone points out that all the books she reviewed in her paper appeared to be influenced by aspects of the authors' own life experiences and life stories.

Many issues arise about analyzing stories for research. One question to address is: can a fictional story based on true collective experiences be used as a research source? This is related to stories, collective stories, presentation of stories and the whole notion of memories, their reliability and false memory syndrome. How different is this type of storytelling from stating that 95% of working mothers had a significantly lower level of self-esteem and that 93% of these mothers related this lower self-esteem to frowns and criticisms received from extended family members, other mothers and teachers when discussing truths.

Richardson (1994) observes that qualitative researchers often discuss the importance of the skills and aptitudes possessed by each individual researcher. This suggests and implies that the best instrument is the researcher rather than the questionnaire or survey. Reading this supported my strong feelings of responsibility to use my knowledge, my experience and my skills to produce the best research I possibly could.

Memory Work

There are a number of researchers whose research on memory work has informed this study. The memory work processes that are particularly intriguing come out of the work of the German feminist scholar Frigga Haug (1987) who with her colleagues have been credited for being the first to recognize and develop memory work. The major theory underlying their work suggests that subjectively significant events, which are remembered and the way they are subsequently constructed, play an essential role in the construction of one's self. This theory postulated by Haug *et al.* strongly points to memory work as a method. They argue that a basic premise regarding memory is that all that we remember constitutes a relevant

trace – for the formation of identity and that this is because it is remembered. They also argue that memory work is only possible when the subject and object of the research are the same.

While the research on doing memory work is extensive, as we see in the studies (Haug, 1987; Crawford, Kippax, Onyx, Gault and Benton, 1992; Mitchell and Weber, 1999), the theme that unifies these studies is the idea of "working with memory." How we remember the past is clearly influenced by many factors, our perceptions which are our own truths, our pain, our individual skills at storing, retrieval, and expression of our memories and in the case of mothers of children with special needs, their particular stage of the mourning process both at the times that the memories were encoded and at the times they were recalled and shared. These factors all impact memory work. The amount of time after the event, before the memory work being explored may have an impact on the memories as well. Mitchell and Weber (1999) start their chapter on working back through memory (p. 46) with a quote from the novelist Toni Morrison:

> Memory (the deliberate act of remembering) is a form of willed creation. It is not an effort to find out the way it really was... The point is to dwell on the way it appeared and why it appeared that particular way. (Morrison, 1996, p. 213)

I couldn't agree more with this choice of an introductory quote, as well as with the quote itself. A great deal of time and effort has been devoted to investigating the validity of memory. The whole concept of false memories has received a great deal of attention (Haaken 1998). What I am most interested in is what the participants in my group remembered and how they remembered it, as well as the perceptions and emotions around those memories.

What they remembered happening was much more interesting and important to my study, than what actually happened, if it's even possible to know what "really" happened.

Annette Kuhn (1995) in her book *Family Secrets: Acts of Memory and Imagination,* makes a comparison between memory work and trying to solve a mystery novel. I can only respond, as she insinuated, if only it were so easy. Both Haug *et al.* (1987) and Crawford *et al.* (1992) suggest that there are many benefits to doing memory work within a group. Mitchell and Weber (1999) suggest the following as key advantages to the group approach. (p. 63)

- A group has a wider base of theories, judgments and opinions that may be pertinent to any one theme than an individual has (i.e., individuals can share the workload of acquiring appropriate knowledge).
- There is a level of analysis inherent to group work that is not available to the individual (for example, providing for a type of "compare and contrast" in terms of experiences).
- "Writing against the interpretation of others" (Haug *et al.*) encourages self-examination for clarity and precision since the rememberer has to make herself comprehensible to the others in the group.
- Sharing stories within a group brings out the social rootedness of personal experience. (adapted from Haug *et al.*, 1987, *Female Sexualization*)

Of particular relevance to this study, is memory work as a methodological approach to working with mothers of children with special needs. It appears from my literature review, that there have been some excellent studies looking at groups of women using memory work to understand different phenomena. Haug (1987) used memory groups to look at how women

recall their own bodies. Crawford *et al.* (1992) used memory work to look at how women recall their childhood differently than from men, Mitchell and Weber (1999) used memory work to study teacher's memories of being young children in school and O'Reilly Scanlon (2001) used memory work to study teacher's experiences of art education when they were young children. In the literature on post traumatic stress, the need to tell one's story over and over again, a form of memory work, is part of the therapeutic process as well as identifying the issues of pain. My review of the literature suggests that mother's using memory work to understand their experiences with the diagnosis and care of their children with medical problems or disabilities has not been well investigated.

Strengths of Using Memory Work

The initial "texts" of memory work are written memories. Crawford *et al.* (1992) suggest there are special advantages of memory work. First, memory work allows for an engagement with the past. Initial memory texts, the memory themselves, are said to differ from narrative accounts and to some extent, case histories, as they describe what is significant to the participant. It is based on the assumption that what is remembered is remembered because in some way it is problematic or unfamiliar and in need of a review. This is one of the main reasons I used memory work with the participants in my study. I believe that we needed to really get "down to work" and identify their perceptions of the problem as we developed terrain which was previously perhaps cautiously avoided.

Another advantage of working with memories is that the individual's memories provide the medium in which their actions are given direction and evaluated. Crawford *et al.* (1992) strongly believe that this is a method "par excellence" for exploring the processes of

the construction of self and understanding the ways in which emotions, motives, actions, choices and moral judgments play their part in that construction. It gives us insight into the way people perceive the social world and in so doing, transform themselves and it. They suggest that memory work involves at least three phases: 1. The collection of written memories according to certain protocols; 2. The collective analysis of those written memories; 3. Further reappraisal – a reappraisal of the memories and their analysis in the context of a diversity of theories from various academic disciplines.

John Kotre (1995) offers that phenomenologists used the term "memorial container" when describing the body in relation to memory. Kotre suggests that one must touch old objects, smell old aromas, hear old sounds and stoop down to the level of a little person, to recapture the experience of childhood. He suggests that one will experience memories more deeply if they are embodied in gesture and movement. In this study, I encouraged the participants in the use of various prompts, such as pictures, objects, a special event like the first day of kindergarten, or different types of music, to stimulate and recapture their memories and assist us in our memory work. I was interested in what these prompts would do in the way of triggering and retrieving emotions and memories that these women would write about. Memory work was utilized in two ways. In the group sessions, recapturing memories of the child with special needs and after the program recapturing the memories of the program itself and how they perceived and remembered the impacts which the various writing exercises and the writing program, had on their feelings, dealings (i.e., problem solving), and on their passages through the mourning process. I simultaneously searched my own memories of the program and my associated perceptions and emotions, as well as what I

recalled of the others as they participated in this process (i.e., the writing group and exercises).

These are the underlying concepts that I bring to the present methodology and research. That is, looking at the phenomenon from my own eyes, reflecting upon themes using my writing and the writing of others in similar situations, considering the parts and the whole, thinking and remembering, all within the context of the value of writing as therapy for mothers of children with special needs. I present the information in terms of common themes and personal narratives (i.e., their "stories").

Writing Groups

The process of writing and/or storytelling, particularly when being used in a therapeutic context, can often be facilitated by sharing stories in a group format. According to Gere (1987), writing groups have been in existence for more than two centuries, dating back as early as 1728 when Benjamin Franklin met weekly with a group of peers to comment on current events and discuss their writings. Nonetheless, writing groups continue to be "discovered." Gere suggests that this continual rediscovery is an excellent demonstration of the extent that they have remained "on the edges of educational consciousness." My own review of the literature illustrates that overall, writing groups provide a positive experience for the participants and can result in a number of beneficial outcomes, not the least of which is the sharing and focusing of ideas that goes on within a writing group.

Bentley and Butler (1988), well known and respected for their "Lifewriting Workshops" and education conferences, provide the rationale for using a writing group as a format for writing, particularly personal, and autobiographical writing, where the process

may be considered "a private and solitary venture" by explaining that lifewriting, although private, is also a social activity. They suggest that meeting with other people, and discussing their experiences and reactions, appears to help the group member to remember more. After an initial brainstorming period, participants begin to write, usually on their own. When they come back into the group, they read their writing aloud to the other members. So not only must one write, but just as importantly, one must read their writing aloud, which allows them to "hear" their thoughts and become reacquainted with themselves.

Sometimes a person has so much on their mind, so many conflicting thoughts and emotions, that it's not always easy to sort them out, or even to express them. The basis of a good writing group is to formulate a level of trust whereby the writers feel comfortable sharing what is on their mind, which is often a reflection of a particular feeling or emotion. Once these feelings and ideas can be discussed, then they become clearer to be written down. Trust, then, is an integral part of a successful writing group. Bentley and Butler (1988) suggested that informal conversation within writing groups leads not only to writing, but to better self-understanding.

> In the beginning stages of writing, when the writer is struggling to express vaguely realized ideas and images, informal conversation works as a powerful motivator because it allows the writer to try out ideas...the give-and-take of ordinary conversation allows ideas to take shape in words ... (Bentley and Butler, 1988)

These authors write that it is within these writing groups, where people can share their experiences, that helps them to remember more. Talking to others often triggers thoughts and memories about other things. Ideas are expanded upon. As memories are

retrieved, others are stimulated and the group work becomes an important social and therapeutic occasion. As well, the set-up of writing groups, where participants are encouraged not only to write, but to share ideas, gets people to talk about themselves, something they enjoy doing.

Other benefits of writing groups are the ability to formulate questions and solve problems (Dias *et al.*, 1992). Dias *et al.* write that a collaborative writing situation, or writing workshop, allows a person to formulate questions and solve problems through exploratory talk in a small group setting. They go on to say that it is within this working group that participants develop skills in decision-making and judgment as they practice with other members of the group, which helps them see things they might not have otherwise seen on their own. Through discussion within the group, then, new ideas emerge.

Dias *et al.* (1992) also discuss the downfalls of writing groups, the most telling being when there is an inconsistency of participation. They write that other members become discouraged or frustrated when "arriving at a meeting only to discover that the others are missing or unprepared or not fully participating" (p. 79). Other disruptive behaviours include whispering, gossiping or interrupting while others are speaking. Nonetheless, there continues to be support for the benefits of writing groups. Brooke, Mirtz and Evans (1994) write, "Learning to respond to writing and learning to understand and use the responses of others are both situated and developmental experiences" (p. 167). It is important that trust is developed to allow group participants to freely explore their feelings in the form of writing. Furthermore, the need to write is seen as a positive state.

Mary Cullinan (1997), in her monograph *Creating an Adult Writing Group: Composing Ourselves,* is very effective in describing and delineating the many important

values of writing in a group setting. She summarized the aspects that she found most compelling in her literature review, as well as in her own study of a group of individuals who were clients of a community health centre in a suburb of Montreal. Her list was as follows:

- Writing in a group setting helps participants to organize their thoughts in written form.
- A caring and responsive group provides a trusting environment for people to try out their voices.
- There is the give and take inherent in group discussions where people willingly give each other a chance to be heard, because they know their turn will come.
- Writing in a group setting can provide emotional relief.
- Finally, there was the aspect of writing for posterity – to leave something of ourselves behind in our own voices – to plant trees for future generations to enjoy, to remember. (p.18)

In her monograph on creating an adult writing group, Cullinan explains that her writing workshop was not meant as a form of therapy, but as a way of introducing her participants to "another way of listening to their thoughts, of reviewing important events of their pasts and of appreciating the sounds of their voices" (p. 3). She suggests that in her group, the writing workshop appeared to provide the participants with an opportunity to articulate and share thoughts with others, before writing them.

Cullinan describes the process she viewed of her participants reading their work aloud, developing trust and feeling more comfortable in the group setting. She explains the novel and positive experience her participants had when they were told that the only rule for their writing was to "listen to their own hearts and record their thoughts in the voices they

knew best, their own." (p.4) She found that placing content (what they wrote) and feeling (how they felt about what they wrote) at the centre of the workshop, with little or no attention to technique, freed the participants from the worries of correct writing. It allowed them to think about what they wanted to say, before they worried about how to say it. She describes the recognition of writing as a process that evolves as the writer is encouraged to share his thoughts, listen to how his thoughts sound, listen to the perspectives of others and hear what he wants to say.

In her group, Cullinan notes that talking and writing became intertwined. These intertwined processes of speaking, listening and writing are essential to therapeutic catharsis as well as critical thinking and problem solving. This may be best accomplished in a group where reading, writing and storytelling can all take place.

Focus Groups

I conducted my study primarily in group settings, an approach that I also use in my clinical practice whenever possible. Therefore, I draw on the work of focus groups, noting in particular what the researchers have described in terms of the origins of focus group work, as well as its guidelines, benefits and limitations. Krueger (1994) has defined a focus group as "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (p.6). The basic concept of a focus group as being therapeutic, is the notion that people will be more forthcoming in a group comprised of like individuals who share common problems (Lederman, 1990). After decades of use, this system has still remained largely within the domain of market research. Beginning in the mid

to late 90s, however, there has been increased recognition of the value of focus groups in such areas as education and health and social services (Powell and Single, 1996).

For the purposes of my research, I have chosen to discuss my pilot study in terms of a focus group. Janesick (1994) suggests the pilot study allows the researcher to focus on areas of investigation which may have been unclear. This part of the study, Janesick adds, may be used to evaluate certain interview questions and allow the researcher an opportunity to develop and even solidify a rapport with the participants and establish communication patterns which appear to be effective.

This upsurge of interest parallels an increased reliance in the public domain on qualitative methodology to provide in-depth insights into the thoughts and behaviours of the users of various services. As Krueger (1994) explains, a researcher can learn how many people are dissatisfied with a particular service or product by means of a quantitative survey, but must rely on qualitative research to discover why they are dissatisfied. This is so true in the understanding of mothers parenting children with special needs. Many quantitative studies have concluded that this situation can cause stress, feelings of being overwhelmed and even depression. However, few have attempted to qualitatively understand the highly complex and intense situations and emotions this group must deal with or more specifically to identify and understand the contributors to these feelings. For example, the knowledge received when having been dealt the information that one's child is sick and/or disabled, is enough to elicit a state of confusion, depression and feeling overwhelmed. However, how do the mothers' perception of the professionals and their interactions with these professionals increase or decrease these feelings?

In an address on meeting the information needs of health care patients, Tang, Newcomb, Gorden, and Kreider (1997) report that they had examined patient information needs from the perspective of clinicians, educational software vendors, and patients. They found that the most instructive information came directly from patients in focus groups. This is consistent with one of the premises of this study which is that valuable information regarding the child with special needs and his or her mother comes from the mother.

Setting up a Pilot Study

In running and directing Centre Multidisciplinaire (MDC) and trying to cater to the needs of the clients and community at large, I am frequently adopting, modifying and developing programs. In 2000, I became interested in developing a new program for mothers. I had been facilitating parent support groups for years and had gradually introduced more and more reading and discussion into these groups. At the same time, I was taking courses as a Special Student and thinking about possible research ideas. During this time, I was learning of the value of writing for problem solving, and its therapeutic benefits and I was beginning to use these approaches in my clinical work.

At the time, I had been facilitating a very informal support group for mothers every Monday morning and I discussed with them my thoughts of a writing group. I developed ideas for a pilot project and designed the focus group, based on methodological ideas I had just learned in a graduate course on groups. I invited the mothers from my informal talking/storytelling group to join this proposed writing group. I also advertised the program in a local newspaper under the community section and in MDC News, a newsletter put out by my clinic. Eight women volunteered, four from the Monday morning mother group and four

new members. As I knew I was developing the program and might use the data as a pilot project for a potential Ph.D. research project, I did not ask for any fees for this group. I explained before starting that this may some day be used for research for a Ph.D. thesis and I invited them to be participants and co-researchers. They responded enthusiastically. They all agreed, as well, to sign consent forms in the event that I and my research would be accepted to the doctoral program.

Prior to the beginning, I met with each of the participants individually to learn more about their feelings and experiences with reading and writing (see Appendix D). These interviews were audio taped and transcribed. The tapes were destroyed after transcription. During the 1st session, I discussed my ideas for a writing group, as well as my goals and objectives and asked the participants to share what brought them to this group. I was explicit about the possibility that this may be used as a pilot study and explained to them how they were like a focus group. I shared and discussed my proposal, which would be submitted as an application for a Ph.D. program. The group expressed excitement about sharing in this process and we joked about applying for "our Ph.D." I found the fact that the participants were like co-researchers served to engage them more. As we went through the ten sessions, we discussed the value of each exercise and developed new ones. Our need to define "mothering" and "mothering a child with special needs" and "advocacy" became quite apparent. The focus of this group was not only on using writing to deal with being a mother of a child with special needs, but also discussing and critiquing the various approaches in an attempt to develop a writing program specific to this group (i.e., mothers of children with special needs).

Janesick (1994) suggests that "before devoting oneself to the arduous and significant time commitment of a qualitative study, it is a good idea to do a pilot study" (p. 213). In the end, I decided to consider my first writing group to be my pilot project, which in many ways was similar in structure and form to a focus group. I carefully noted what worked and didn't work with regards to the group. Using the participants as consumers, I noted their comments and concerns for use in the development of my study procedure. During this phase I attempted to try out my ideas and "experiment" with different approaches and techniques. I wanted to design an atmosphere whereby I could find out about the issues and concerns experienced by mothers who had children with special needs. By structuring the pilot group along the same lines as focus groups used by marketing companies, I was able to set up the parameters by which I could monitor what these mothers had to say, and of course, write, about the issues and concerns in their lives. Memory work was one of the primary techniques encouraged and utilized.

It was in this group that the participants could try various styles of writing as a method of self-expression in order to tap into those issues and concerns. As well, the group would discuss their work and share and discuss the works of the other members. With an open mind, we would examine descriptively, which methods of writing worked for the members of the group and the group as a whole. I looked at the collaboration, the process of writing and the final product.

Working within the structure of a focus group as a type of "memory work in progress" was also in line with my attempt to incorporate qualitative data into my study. That is, it was within the safe arena of a focus group that I wanted the mothers of children with special needs to tap into their feelings, emotions, concerns, memories and issues through the

process of writing, with the goal of determining the therapeutic value of that writing in identifying those needs, emotions, issues and problems, and hopefully finding solutions and/or relief.

In this pilot study, I was looking at the connections between writing as a problem solving process and as a therapeutic tool, with regards to the development of a mother's emotions and the expressions of these emotions in dealing with a child with special needs. Essential then, was to identify participants who liked to write, or at the very least, viewed writing as something they would like to do.

The Project: Writing Group for Mothers

After completing the pilot project, I refined the writing program and once again offered it to those in the Pilot Project, as well as others in the clinic and the community news plus our clinic newsletter (See Appendix C).

Prior to starting the focus groups and the project itself, participants were asked to participate in a semi structured interview, (see Appendix D). Once again, these interviews were taped and transcribed. The tapes were destroyed subsequent to the transcription. The participants were given a package with the dates and topics of each group (see Appendix E) and a sample of the questionnaire to be completed after each session (See Appendix A).

The writing group started with eight members and ran for 10 sessions, once a week for 90 minutes. Due to various personal life issues that affected attendance, there ended up being an average of five members who attended each session. In some sessions, only two members attended and one time, there was only myself and one other participant. The participants of the group wrote on topics that they selected themselves. Some writing

exercises took place during the sessions, while others were done on their own time, outside of the group setting. Each week, participants read their written work aloud and responded to each others' writings, a process which they all reported that they enjoyed.

The format of the ten sessions was unstructured in an effort to encourage writing, listening and discussion. To facilitate the exercises, I gave the group some ideas and explained some of the supporting information to illustrate the benefits of various forms and styles of writing. For example, I explained to them that it has been suggested that writing an angry letter, whether it is sent or not, can be very helpful in reducing or even alleviating those feelings of anger.

I chose to form an agenda for the group and discussed with the participants if they preferred a directive or non-directive approach. They reported that they felt more comfortable with a more directive, at least structured approach. The following are descriptions of each of the ten weekly writing activities:

SESSION ONE: The participants were told that they could write their introduction prior to the first session or that they would be given time during the first session to write their introduction. All participants were given an opportunity to do some writing and introduce themselves. Each participant read their introduction to the others. This was followed by a short briefing session regarding the nature of the research and issues of confidentiality (i.e., that I am bound by the Order of Psychologists of Quebec), that I expected them to keep all information shared in the group, within the group and that confidentiality would be maintained. I explained the necessity for all participants to do the same. That is, that they could discuss issues, topics, in general terms with others, but that they should not disclose the names or any personal information regarding the other group members. The participants were

assured that if they felt any discomfort or stress during the program and for six months after, I would be available to them for emotional support. Cole (1991) points out that when individuals are re-involved in any form of life history, including self-study and memory work, they are encouraged to recall and confront past events. These events may not be pleasant to remember. The individuals may not come through this process "unblemished and carefree" (p.193). Crawford *et al.* (1992) suggest that groups with a skilled facilitator may be able to relieve anxiety, enabling the writings of memories and collective discussion and to redirect attentions. This of course was my belief in studying writing as a therapy. I was excited to hear in storytelling, and see in writing, the emotions and perceptions of my participants. I felt comfortable in my skills as a therapist to help the participants with any arising difficulties or conflicting emotions and was very clear that I was available to them.

Sample poems and prose that had been published about children with special needs were read and given out to the members and there was a discussion of the writing activity for the following week. The participants were asked to sign a waiver. (See Appendix F)

SESSION TWO: The participants wrote their own poetry related to being a mother of a child with special needs and/or their critique of a poem or piece of poetry or prose that I had given out the previous week, or a piece that they had found themselves. They were encouraged to choose whichever activity they preferred (i.e., writing a poem or critiquing a poem written by someone else). Some of the participants chose to critique the poem *The Dragon Slayers* (see Chantal's story in Chapter Five), which was written by one of the members who had participated in the pilot group and continued in the writing group.

We read our written work aloud, then we did an ink shedding activity - an activity where individuals respond in writing to each other's written work, offering opinions and

discussion, but not judgment (McGee, Nagel, and Moore, 2003). The participants responded in writing to each other's poems or critiques and the responses were passed around so that people had an opportunity to read each other's poetry and responses.

SESSION THREE: We worked on the reading and writing of angry letters. The writing of an angry letter has often been described as an effective activity to reduce anger and facilitate emotional catharsis (Vance 1998, Epston 1994, Adams 1990, Freedman and Combs,1996). Some of the suggestions made for this writing activity were writing an angry letter to a doctor, therapist, teacher, family member or even, the special needs children themselves. One parent had chosen to write to the children who teased her daughter in the school yard, another wrote to a teacher, one wrote to her child's doctor, one to a psychologist.

SESSION FOUR: The participants were asked to write whatever they were inspired to write while listening to two types of music. The instructions were that they choose two different types of music, for instance a marching band and classical music or rap and blues, one being more slow and one being more rhythmic or moving. They were to write whatever came to their minds while listening to the music. We also played some music during this session, giving the participants an opportunity to write together while being inspired by music.

SESSION FIVE: The participants were asked to bring in an object related to their child, that they wanted to write about. One participant brought in a handprint of her child that he had done in kindergarten. This was very meaningful to her as it was through his handprint that they were able to diagnosis his genetic disorder. Another mother brought in her child's baby bottle which she could never throw away. Another brought in a report card. The

participants wrote together using these objects as prompts. Some prepared their writing beforehand and continued during the group time.

SESSION SIX: The activity was to write a letter of gratitude or praise (i.e., thanking or praising someone for their good work, kind words or for their help and support). One wrote to a dear friend, some wrote to professionals and one wrote to her child with special needs. We also listened to a story on audiotape, where a grown man whose mother disregarded advice to institutionalize him, thanked his mother for believing in him and not giving up.

SESSION SEVEN: Involved writing about a memory. This could be a positive or a negative memory. It could be an intense memory or a less vivid one, a memory that flashed through their mind or one that was stuck in their mind. They worked to retrieve and experience these memories and then write about them. They were asked to describe the memory, in writing, with an attempt at using all senses (i.e., to see it, hear it, even touch, smell and taste it) They were asked to describe the associated feelings and perceptions and to discuss how that memory makes them feel today. Although all the sessions used memory work, sessions five, seven and ten were particularly useful in studying this process.

SESSION EIGHT: Focused on writing an advocacy letter, message or policy statement. This activity was inspired by many emotionally-charged discussions during the pilot project, resulting in "If only we could do something about this…If only someone would listen." The participants were to write a letter, policy and/or recommendations to an institution, administrator, board, committee or government office, where they want to advocate, suggest policies and/or facilitate research, or changes in clinical or educational practices. A trend which appears to be more and more visible in the literature as well as in

my clinical research observations is that of parents advocating for their children and becoming involved in the making and changing of governmental policies influencing the medical and educational care and services of children with special needs. These policies are generally developed and passed by politicians who lack the essential knowledge only possessed by those personally involved.

During this session, the participants had an opportunity to write their recommendations regarding changes in policies, related to the educational and medical care of their children.

SESSION NINE: The participants were asked to write an advertisement or a job description for either a mother of "typical" children and/or a mother of a child with special needs. We often discussed this impossible job description (i.e., the many responsibilities of a mother in a humorous way). This writing activity was initiated from a discussion in the pilot group about the lack of understanding encountered while working and living this highly demanding, exceptionally important job. This activity was in line with the work of Crittenden (2001).

SESSION TEN: Participants were asked to bring in a picture related to their child with special needs and write about the picture, using it as a prompt. The underlying rationale for this writing activity was very similar to that of sessions number five and seven in that the participants were using a visual as a memory prompt. A picture is a prompt which has often been studied and is unique as it richly captures a memory or a moment, of a person or people, in time. The picture also captures many elements of non-verbal communication (i.e., facial expressions, posture, dress and proximity between people, etc.)

At the end of each session, there was a discussion of the next week's focus. For each session, the participants were encouraged to come prepared with their writings. They were, however, not pressured in any way. After each session they were asked to fill out a questionnaire (see Appendix A) about their perceptions and their feelings regarding each session. A copy of these questionnaires was in the original package. As well, they were given out each week after the session. The participants were asked to complete them immediately after the session or take them home and return them at the next meeting. As well, the group members were asked to do at least one journal entry each week, even if it was just one paragraph. I did not impose a limit on the maximum number of words they should write. I also offered to respond to the journal entries by writing to the authors, if they so desired.

After Week 10, we decided as a group to hold four more sessions, where the participants came together and summarized the 10 weeks. During the first two sessions, we talked and wrote describing how we felt about our work, for example what we enjoyed best and what we enjoyed least. Many of the participants wanted to discuss putting their works together in a collection and having it published. This seemed to address, at least in part, their need to advocate for change, their need to be heard, and their need to be their child's voice and the voice of mothers raising children with special needs. The participants were given copies of all the written work to date, they read them and many of them wrote comments. The next two weeks we brainstormed about a book, wrote an introduction and made a list of chapter headings which were thematic in nature (see Appendix G). In a sense, these participants acted as co-researchers, consistent with the suggestions of Maykut and Morehouse (1994). This was particularly evident while we organized the written works, developed themes, and then decided if we wanted to divide the work by style of writing (i.e.,

poems, letters, journal entries), or by themes of writing (i.e., anger, joy, guilt). The suggestions made and the underlying rationale for the suggestions were noted for further analysis. The participants then wrote down the themes as if they were chapters in a book, a book that would be semi-autobiographical, that is, letters, poems and stories written by mothers with children with special needs. Finally, four participants were asked to participate in a post-project interview facilitated by a semi-structured questionnaire (see Appendix H).

Participants

The only eligibility criteria established was that the participant was a mother and that she had at least one child who was diagnosed with a developmental disability, and not solely a chronic medical condition. The reason that mothers of children with a chronic illness only were not included, was that I wanted to focus on the issues and emotions around mothering a child with developmental delays and behavioural difficulties. Some of these issues would include the knowledge that the child may always need to be taken care of. Also this group is unique for having to struggle with additional issues such as explaining or not explaining to others why the child is behaving in an immature or inappropriate way and finding an appropriate educational setting. There may be more guilt and blame related to "bad" behaviour.

For the actual writing project, some members from the pilot group expressed their desire to continue, as well there were four additional members recruited through the same means as in the pilot study, (i.e., advertisements in newspapers and through Centre MDC). I decided to invite and allow the participants from the pilot project to continue in the project as they were very interested and involved and felt part of the group and part of this project.

They reported feeling that the experience had become part of them. As well, the process was continuous and not finite; the women felt that their continual growth and experiences would allow for ongoing benefits. Each time they participated in the exercises, even the same ones (i.e., an angry letter), new experiences undoubtedly emerged. An interesting observation was that some of the most involved women were from the initial group. Three out of the four women I focused on in the "stories" analyses were from this initial group (i.e. Pilot Study).

One father volunteered, but he was not accepted into the program. This decision was taken as he may have altered the dynamics and comfort level of the group - a phenomenon known as the Peacock Effect (Krueger, 1994). It was interesting to note, however, that he had custody of his children, was the primary caretaker, was an exceptional advocate for his children and was an active volunteer in groups such as the Special Needs Advisory Committee of his school board. He was very masculine, but "maternal" would be a better word to describe him. He was the only father who volunteered and his profile fit.

No other exclusion criteria was utilized. If a respondent to the recruitment process was a mother with a child with special needs, and she expressed a desire to write, ability was clearly not a factor. She was not only included in the study, but welcomed. At some point during the process I joined the group, writing and discussing with them. I believed that the potential risks of doing this were greatly outweighed by the potential benefits. That is, my initial discomfort of sharing my story and my concerns about balancing the roles of participant and researcher were not as strong as the benefits I had realized were inherent in becoming a participant and involving myself in the study.

Data Sources

Connelly and Clandinin (1990), suggest that a number of data collection methods become possible as the practitioner and the researcher (in this case the mothers and the researcher) work together in a relationship that is collaborative. They suggest the following as a list of possible data sources: field notes derived form shared experiences, journal records, transcripts of interviews, observations made by others, storytelling, letter writing, autobiographical writing, other documents such as classroom plans, newsletters, list of rules, pictures and philosophies. Clandinin and Connelly (2000) further discuss and expand on all these methods and add conversation, life experience and family stories.

Janesick (1994) suggests that most often qualitative researchers use a combination of methods such as participant observation, interview and document analysis. She suggests that over the thirty years prior to her paper, educational researchers and other studies of human services have used case study methods, oral history, including narrative and life history approaches, grounded theory, literacy criticism, and ethnographic approaches. A good example of using letters to participants in a research framework can be seen in Mickelson's (2000) work with mothers of boys with severe behavioural disorders.

Connelly and Clandinin (1990) explain the many differences in styles of writing. Their discussion of writing and temporal differences was very helpful. They explained that storytelling and autobiography tend to be located in the past; while picturing and interviewing are more likely to be located in the present; and letter writing, journals, and participant observation all tend to be located in the future.

I found myself conversing with my participants and in a way with myself, even after the writing group was over. I still kept anecdotal notes on what clients said about reading and

writing and read more professional and popular literature related to writing, reading, storytelling and mothering. I continued buying every new autobiography written by mothers of children with special needs (there are new ones every time I go to the bookstore).

According to Connelly and Clandinin (1990) a primary tool of narrative inquiry is field records that are collected and recorded through participant observation in a practical setting which is shared, while journals are another such useful source. Journal records can be kept by participants, researcher or practitioner. The instructed interview is another data collection tool in narrative inquiry. Connelly and Clandinin suggest that interviews are conducted between the researcher and the participant, transcripts are recorded, meetings are made available for further discussion, and become part of the ongoing narrative record. They suggest many very powerful examples of the ways of using individual's lived stories as sources in narrative inquiry.

In living the narrative inquiry process, it is suggested that we are one person. We are also one in the writing. However, in the writing of narrative, it becomes important to sort out whose voice is the dominant one when we write "I." We are, in narrative inquiry, constructing narratives at several levels. We are telling personal narratives as well as the jointly shared and constructed narratives that are told in the research writing. Narrative researchers are often compelled to go beyond the telling of the lived story to telling of the research story. In the process of writing the research story, the thread of the research inquiry becomes part of the researcher's purpose. In some ways the researcher moves out of the lived story to tell, with another "I," another kind of story.

This is the process I undertook. I placed myself within the research, then I worked with and facilitated the process of others' writing and the telling of their stories. The tools

and materials used in this study included field notes consisting of observations, anecdotal comments made by the participants during the sessions, transcripts of pre- and post-interviews and written questionnaires completed after every session, as well as the actual writing produced and prompts used for writing.

I concur with Mauthner and Doucet (1998) when they explain that the data analysis is not a single, separate phase of the research, when we analyze the transcript of the interviews. They describe data analysis as an "ongoing process which takes place throughout, and often extends beyond the life of the research project" (p. 124). There is no question in my mind that this project has been a continual data collection and data analysis process. As I transcribed the interviews and wrote the data analysis, I found myself partaking in more questions and more discussion with the participants. I found this opportunity to be one of the strengths of qualitative research, where I could keep digging for answers in an attempt to develop a comprehensive understanding of the data and the phenomenon under study. From the inception of this idea until today, I continue studying and analyzing the process of storytelling as it contributes to the therapeutic and research processes.

Mauthner and Doucet (1998) suggest that an important issue while in the data analysis phase of the study is keeping the voice and perspective of each respondent alive, while at the same time recognizing the role of the researcher in shaping both the process and the product of the research. They further suggest that to be reflexive about our data analysis we need to locate ourselves socially in relation to our respondents. They suggest that we attend to our emotional responses to the data and that we also evaluate our own theoretical interpretations of the respondent's narrative and that we record these interpretation processes for ourselves and for others. They suggest that this process will help the researcher gain

control of the often undefined boundaries which may exist between narratives and our interpretations of those narratives. The analysis includes many techniques of evaluating the written work for content rather than quality or technique.

Connelly and Clandinin (1990) suggest that in the writing up phase of a study, it is often hard to distinguish when the writing of the study actually began. They explained that there is often a sense that writing began during the first conversations with participants or even earlier, for example when the ideas for the study were first formulated. I kept feeling that I was not done collecting my data. I was continually writing and collecting notes, information and anecdotes from before I started my first group, to long after the last "formal" session.

I was comforted by one of Connelly and Clandinin's (1990) statements which suggested that even though there may be the moment when the researcher believes that they have completed data collection and are ready to write the narrative, there may be the need for more discussion with the participants. They suggest that data is collected until the final document is completed. I still keep in touch with many of the participants. I often think of having just one more group meeting, one more interview or maybe write them a letter summarizing the research, thanking them and maybe even eliciting a written response from them. In a few instances when writing up this research, I've called them and asked them to elaborate on a thought or anecdotal comment, which I had earlier recorded.

Connelly and Clandinin (1990) suggest that whether one feels that the appropriate task is broadening, burrowing, restoring, or all three, the process of additional data collection is quite likely a possibility during the latter stages of writing. This comment was comforting to me as I continued to listen, read, and write. Thus, the authors stated that the process of

writing the inquiry and the process of living the inquiry were activities that run side by side and may shift one way or the other, but that always work in tandem.

Data Analysis

Maykut and Morehouse (1994) suggest that their approach to data analysis is to understand more about the phenomenon that is under investigation while they try to describe their findings with the least necessary amount of interpretations. They explain their desire to stay close to the feelings, thoughts and actions of the research participants as they relate their focus on inquiry in a broader sense. They explain that their data is not grouped according to predetermined categories and that the importance of its use in analysis emerges from the data itself through a process they refer to as "inductive reasoning." They suggest that the "constant comparative method is one way to conduct an induction analysis of qualitative data" (p. 127). Maykut and Morehouse describe the process of working with a research team and its usefulness in qualitative data analysis. I used many of their suggestions, in relation to working in a team, as well as their systems of category coding, visual presentation and refinement of categories, particularly with regards to the data analysis. My participants were members of our research team and together we worked on categories and themes, for example our process of brainstorming themes for chapter titles in a book (see Appendix G).

So in essence, my data analysis included self study, my thoughts, my memories and perceptions and my written work, then analyzing features about my participants, analyzing their stories and their thoughts, and all of the materials, that is, field notes, anecdotal notes, written materials, including poems, letters, prose, critiques etc., choice of prompts and any other materials and information shared with me in interviews and questionnaires.

The analysis includes evaluating the participants in a number of ways. Firstly, who are the participants? Why did they choose to join the group (i.e., to help in the research project, to feel better and/or to have a voice, to be heard, to make a difference)? Did they all have the same motivation, or were they all coming from different places, with different agendas, different needs and/or different objectives? Did they all like to write, or did they not really like to write, but they thought writing may help them deal with their daily stresses? Were they comfortable writing? Did they feel good about their writing?

This first level of analysis was to really understand the participants, who they were and what their story was. The written work of all the participants was analyzed in a number of ways as well. Before starting to analyze the participants' writing, I reviewed the literature on writing as therapy, as well as books written by mothers of children with special needs. This was done to get an understanding of what mothers were writing about. It was necessary to look at the differences as well as the similarities in these books to see if there were common themes emerging, such as the mother blaming herself, or the good and bad mother themes. This gave me a framework by which I could then analyze the writing of the mothers in the study group, and analyze my own writing. I asked myself if similar themes appeared, and if so, how were they expressed?

I chose to focus on four participants and their writing. I analyzed all the data from my interviews and notes with the participants in the focus and/or writing groups. I questioned how they felt about writing in both general and specific ways, when and if they used writing to help them organize their thoughts. I compared their answers in a post-project interview to the answers they gave before the group had started (i.e., pre-project interview). I analyzed the process of writing and how it made the participants feel. I kept field notes discussing what

people said about how they felt either during and/or after the writing process, and how they felt during the process of hearing or reading other people's writing. Analyzing the process also means looking at which style of writing the participants chose (i.e., if they liked writing poetry, but hated writing a letter), and why they preferred one method over another. I questioned the participants about how the styles of writing made them feel, asking questions such as whether they were able to find solutions to their problems, gain insight, or feel relief from the sharing of their story? As well, I analyzed the responses to the questionnaires that the participants were asked to fill out at the end of every session and the frequency in which they handed them in.

I analyzed how the participants felt about their writing as far as content. That is, were they satisfied with what they wrote? Did they feel that they were able to adequately express themselves? I analyzed their feelings on the process of writing itself, questioning whether it was easy to sit down and write, or whether they waited until the last minute and wrote under the pressure of knowing the group was meeting. Did this affect their writing and if so, was it in a negative or positive way? What were their feelings about the process with regards to its therapeutic value, research value and other issues that arose such as their desire to use their writings for advocacy, for teaching and for sensitizing the professionals?

In analyzing the product, or content, I looked at what people chose to write about. I was looking for their stories, their memories and how they retrieved those memories. Did they need prompts to retrieve those thoughts, and then, what sort of prompts? Or, did their memories bubble to the surface the minute the pen hit the paper?

I analyzed the voice of the writing; does the writer use the first person "I" or third person "she." thus removing herself from the story she may be telling about herself? Does the

writer switch voices mid-stream, and does she change the point of view; that is, does she begin her story from her eyes, and then shift the focus to the eyes of her child with special needs? I looked at how the participants wrote, using different styles. For example, there was one woman who could write a beautiful, eloquent poem, but had difficulty expressing herself when writing using any other style or form. Next, I analyzed the field notes that I had kept, particularly anecdotal comments.

Finally, in order to fully analyze all the data sources within the context of the individual's particular characteristics and life history while creating a comprehensive story, rich in information and insight, I chose to present the data as four stories.

Chapter 5: Data Analysis

Mothers' Writings/Mothers' Stories: An Introduction

We are a group of ordinary women leading ordinary lives. Yet we are all dealing with extraordinary challenges. Brought together by our common struggles, needs, and desires, we are all mothers of children with special needs who meet regularly to share and discuss each others' written works. Our emotions, challenges and discoveries have been expressed through therapeutic writing in the form of poetry, prose, letters and journal entries.

None of us are professional writers, yet we have come to enjoy the experience of writing. By putting our thoughts on paper and reading our works aloud, we have recognized problems and potential solutions. At times we were brought face to face with emotions that we weren't even aware of or that we thought we had resolved long ago!

In short, we have been amazed and relieved to see ourselves in the writings of others. Together we have laughed, cried and been inspired by each others' words. Comforted, we have realized that we are not alone. Strengthened, we have understood the power of the pen. Encouraged, we have learned that we can get up again after we fall.

Our writing began with the desire to get in touch with ourselves and one another. In the end we came away with so much more. Through the written word we are learning to slay the dragons of doubt, fear, isolation, prejudice, anger, despair, helplessness and ignorance. Woven through the writings are the many colored threads of hope, resilience, pain and joy and the never-ending wonder and discovery of life itself.

It isn't always easy to find the time or peace of mind to write. Our chaotic lives so often lack structure and routine. The unexpected is almost always getting in the way. We share our words with you in the hopes that you might find your own discoveries and inspiration. Perhaps you too will feel the urge to explore what lies beyond the ordinary.

I began this chapter with the above narrative, left in the mothers' own words, as it was written by the participants. I believe that they eloquently convey many of the themes expressed in their writing as well as their feelings around the writing process itself.

In this chapter, I will begin by presenting four individual stories in depth. I will then end the chapter by discussing the general themes around mothering a child with special needs and around writing as a therapy, using the writings and spoken words of all the participants.

The following are four narratives about four special people, each portraying an exceptional story of life and of love, of ambivalence, faith, fear, anger and much more. Each story describes the mother's feelings and perceptions regarding her writing and regarding the benefits of reading and writing for herself and for others. For these stories I selected the participants who attended the most sessions, completed the entire program, participated in the pre and post interviews and kept in touch after the project was over.

I present each story by discussing the participants' views on reading and writing before the program, their anecdotal comments during the sessions, some samples of their writings with analytical comments, their opinions and feelings related to their writings and to the writing of others, their feelings on reading, on writing after the program, on the writing group process and on their experiences, and finally about their feelings around the themes that emerged from their writings, the writings of others and discussions of the group as a whole. The information collected using these data sources is presented in the form of a narrative, in essence telling their story through their memories, perceptions and words, both oral and written.

I changed the names of the main characters and of their family members and altered some identifying details to respect their confidentiality.

Sally's Story

"My husband and I were constantly at each other's throats, arguing over discipline and my ability to mother children which was, in my mind at this point nil!"

This quote was taken from Sally's first writing activity during the writing program. Prior to the first session, all the participants were asked to prepare, in writing, a short introduction about themselves. The instructions were vague with regards to content. They were told that they would be asked to read their introduction aloud to the other participants. Sally felt that this exercise was good practice for her reading and writing, and a very positive experience. Sally's introduction was more organized and contained more information than her previous introductions (i.e., in other parent support groups) which were oral and probably more spontaneous.

Sally is a pleasant, energetic woman in her late forties, who has been married for nearly two decades and has three children and a stepson. Her husband is caring and a good provider who owns his own business. Sally openly states that her husband probably suffers from Attention Deficit Hyperactivity Disorder (ADHD) and certainly has impulse control and anger management issues. Sally works part time as a bookkeeper in her husband's business and more than full time as a teacher, advocate, therapist and lots more. She presents herself always with a pleasant and positive attitude.

Sally's eldest daughter is a teenager who is bright, but suffers from ADHD-Inattentive Type, Impulse control problems and some obsessions such as hoarding. She

exhibits poor school performance despite her high level of intelligence. Sally also has twin sons entering their adolescence. Bobby has been diagnosed with ADHD –Inattentive Type and Tourette's syndrome. Ben has been diagnosed with ADHD – mixed type, Tourette's syndrome, Obsessive Compulsive Disorder (OCD), Generalized Anxiety, A-typical Pervasive Developmental Disorder (PDD) and who knows what else. One Integration Aide diagnosed him with "King's Syndrome", a syndrome coined by the aide himself to describe Ben's need to tell people what to do, command specific tasks to be done, such as writing for him, and overall expect those around him to perform duties for him. It should be noted that individuals with Ben's disabilities are often assigned a "scribe" (i.e., a person who writes for them) and they are not considered to be suffering from any made up syndrome such as this (i.e., "King Syndrome"). Ben is the primary concern addressed in Sally's writings. Sally participated in the pilot study as well as in the research project. She read the following at our first meeting of the pilot study.

Sally's Introduction

My name is Sally. I've been married for 14 years and have 3 wonderful children. My daughter Leslie is 11 ½ years old. She was the brightest, most intelligent baby – toilet trained by 18 months, talking in perfect sentences, knowing all her colours and the entire alphabet by the time she was two. But every year in school her marks kept getting worse and worse; not paying attention in class and lots of talking and disrupting others. I had her tested last summer and she has Attention Deficit Disorder (ADD). With constant reminders, lots of nagging and a good tutor for math, she is excelling this year in school and I am extremely proud of the progress she has made.

I also have twin boys. By the time they reached two years old, I was about at my wit's end. The smaller of the two, Ben, was always doing something wrong – destructive, aggressive. My husband and I were constantly at each

other's throats, arguing over discipline and my ability to mother children which was, in my mind at this point nil! We started going to the local children's hospital when Ben was 2 ½ years old. He is now 9 ½ years old. Through the years, he has been diagnosed with ADHD, OCD and Tourette's Syndrome. He is presently being followed by a neurologist, a psychologist and has a part time aide in the classroom at school.

My other son, Bobby, also 9 ½ years old, fell and hit his head when he was five years old. Everything seemed fine for two or three days after but then he started doing these weird things – noises and movements. I had him in and out of the hospital all summer. I even made them do a CAT scan of his head but there was nothing wrong. After a year of constant follow-ups, he was diagnosed with Tourette's Syndrome. It was explained to me that symptoms would have come out eventually, but a head trauma could bring them on sooner. Although Bobby does not need help in the classroom, his temper at times (the neurologist explains it as brain tics) is much harder to handle than Ben's.

Well, this is my story in a nutshell. I hope it was not too long. Thank you for listening.

From the beginning, certain themes become apparent in Sally's writing. Although the instructions for the initial short introduction were vague, that is, to simply write something about themselves, Sally chose to describe herself as a wife and mother. She then focused on the special needs of each of her children. This may be related, at least in part, to the criteria of the group, which consisted of mothers of children with special needs. However, this appears to be consistent with my review of the popular literature. All the autobiographies, memories, and/or diaries written by mothers begin just prior to or around the birth of the child, within the first year of the child's life, when symptoms first appeared, or when symptoms were first identified by the school. But regardless of

the exact time, the mother's story was focused on the child with special needs, as was the case with Sally.

The next observation in this introduction is the good mother/bad mother theme, which is evident when Sally writes: "My ability to mother children which was in my mind at this point nil." This statement reveals that Sally is immediately confiding in the group and sharing with them her feelings of inadequacy as a mother, her judgment of herself and her concern and reflections about how others judge her. Her appraisal of her mothering ability seems to be based on her conflicts with her husband when she writes they were "at each other's throats, arguing over discipline," as well as on her frustrations with her own son, who was "always doing something wrong, destructive, aggressive."

Her need to advocate and take charge and her feelings of it all being her responsibility, came out in statements such as: "I had him in and out of the hospital all summer. I even made them do a CAT scan of this head." The use of "I" and "made them" comes out in other pieces of Sally's writing and are explored later in this chapter.

Her statement, "but there was nothing wrong", reflects Sally's frustration at having her worries dismissed, and is another recurrent theme in the mothers' writing, as well as in many of the books reviewed under popular literature.

Sally refers to "accusations flying" in her direction on her ability to mother her children. She writes that she was sure she was "the worst mother alive." Both statements were consistent with mother blaming, its impact on mother guilt and a poor level of self-esteem. Sally explained that when Bobby, her previously "non-disabled son" was first diagnosed she felt depressed for a week. She began to worry about his future. Her husband told her to stop worrying. However, she felt that this was part of her job. She felt

she was responsible for her children until their early 20's, when they could go out, lead a good life and take care of themselves. She felt "devastated" that he might have limited possibilities for the future. She explained that she did not feel sorry for herself; the differences between her worries and her husband's "don't worry" attitude were consistent with anecdotal notes obtained in this study and in my clinical practice, consistently point to parents having more difficulties dealing with and accepting problems in their non-disabled children, as well as to different "worry patterns" between mothers and fathers.

Pre-project interview.

Before starting the sessions, Sally participated in a semi-structured interview (see Appendix D). On the basis of her responses to the interview questions and the general discussion resulting from these questions, it was revealed that Sally's earliest memories of writing were of when she was a teenager. She explained that she tried to keep a diary but did not have much success. Sally explained that throughout her adult life, she used writing to communicate with her children's teachers and/or to write letters. She often wrote notes to herself and posted them all over her house, in her wallet or someplace where she felt would best enable her to remember things. Nonetheless, she maintained that she was never really a big writer.

The kinds of writing that Sally reported using are consistent with what Britton *et al.* (1975) coined "transactional writing", which he describes as writing used to get things done, most often seen in the workplace or places of education. For mothers, the home may be considered one's workplace. Raising a child with special needs is multidimensional, involving work and education.

Sally explained that she decided to join the writing group because she enjoyed any support group geared at dealing with children who have special needs. This is consistent with Pardeck and Pardeck's (1993) assertion that the group therapy approach can be a powerful vehicle for helping people overcome emotional problems.

Sally felt she would enjoy writing things down, although she felt that her busy life prevented her from finding the time to write. Her objectives and hopes for the writing program were to have some fun, vent a little and share experiences with other people, with the hope that the opinions of others would help her evaluate herself and her life. She felt that she could use their feedback towards self-improvement. She thought that the experience of writing would bring out more truth about her feelings and perhaps help her confront more serious issues, in contrast to the experience of talking groups, which she described as sitting, talking, and being humorous. Sally seemed to see writing as directive, goal-oriented, focused and serious.

Sally also stated that she was good at writing lists and/or notes, letters, diary/journal entries and probably letters. If she had her own private computer that she could lock up, she would prefer writing on the computer because it would be faster than writing with a pen on paper.

Looking back on her life until this point, Sally said she would have liked to have been more diligent in writing in her diary. She recalls numerous occasions looking out the window starting her writing, but never really finishing. She had begun many diaries, doing well for the first week or 10 days and then becoming bored and never continuing. But she felt that having a diary would help her get her feelings out, and would be easier than talking about her feelings. This is consistent with Progoff's (1992) views on the

benefits of journal writing (i.e., to gain perspective on major periods in one's life), or in Sally's case, major ongoing issues in her life. Progoff suggests that this process helps the individual identify inner strengths and new possibilities, as well as discover resources and talents within themselves. This appears to be what Sally was hoping to find in the writing group and the writing exercises.

When asked about what she enjoyed reading most, Sally said she prefers self-help books, particularly about Attention Deficit Hyperactivity Disorder. She also loves reading espionage novels because she finds them intriguing, suspenseful and thrilling, and enjoys other kinds of novels and magazines. This is consistent with the bibliotherapy literature that people turn to learn more about their problem, in this case ADHD and all the issues that go along with it. As well, this is in line with Gold's explanations of the many faces of bibliotherapy, one of which is the use of reading fiction as a sort of escape (Gold, 1990).

Sally described a political book she was reading called *Trevaines* by Robert Ludman. She reported finding it a little difficult to get through with its long political terms and explanations, but she still tries, even reading some pages two or three times until she understands what she is reading. She mostly reads for pleasure and for content, which must be suspenseful and even a little complicated to keep her interest.

Writing selections.

I have included some of the writings that Sally shared with the group. I will present each one, and then discuss them in relation to reading, writing, mothering, emotional themes and stages of mourning such as guilt, anger, ambivalence, sadness, joy, confusion, etc.

I start with her narrative of her son Ben's first day of kindergarten. It is very revealing in a number of areas and it is an excellent example of using prompts in memory work. The following piece of writing was the result of a specific writing activity, where the participants were asked to remember, using their child's first day of kindergarten as a prompt. This writing activity was chosen as memory work to help elicit events, using a prompt of a critical time in the life of a child with special needs and of their mothers. Seligman and Darling (1997) suggest that emotions may emerge and re-emerge during specific times and starting school is one of those times. I have detailed the approach used to analyze this particular text as an example of the many elements involved in analyzing a written text and the richness of the information that can be collected in this way.

Mauthner and Doucet (1998) described an approach of reading a text multiple times, using different perspectives as a basis for analysis. I used this approach to analyze and understand one of Sally's written works. The text contained many themes, thoughts, and emotions described in the literature (i.e., fears, ambivalence, advocacy, isolation, responsibility, the need to be educated and informed and the difficulties with parent/professional relationships). Seeing all these common themes packed into one short narrative, I believe, demonstrates just how powerful the written text can be. This exercise was also a good one to start with as it helped me to stay aware of the interactions between the researcher's "selves" and how this may influence the interpretations of the text.

FIRST DAY OF KINDERGARTEN

I didn't want my son to be labeled as a troublemaker. I didn't want him to be in trouble all the time for things he could not control. Preparations for kindergarten began in May, against the advice of the professionals at the children's hospital where Ben had been going for two years. I decided to meet with the principal early to provide him with all the reports and documents he needed to insure that Ben get the help he needed. I had heard so much about this school, about how wonderful they were with children with Special Needs. Boy was I misinformed!!

This was the beginning of my battle, one which I have been fighting for five years now. True enough, the professionals were right. Although many of the details have been forgotten bottom line was, they kept asking for more information (which I kept providing because I thought they were trying to help) because they were trying to decide if they would accept him in the school or not. Of course, way back then, I was very naïve and believed everything I was told.

It was mid July by the time I found out from the hospital exactly what the school was up to. This is when I decided to educate myself on Ben's right to an education. The Learning Disabilities Association in our area provided me with all the information I needed. The phone calls and meetings continued throughout the summer. I called the school two days before school was starting to find out exactly what was happening. This is when I was told that Ben would have a Special Ed technician in the classroom and a Special Transport bus would bring him door to door. By this point I was no longer worried about his first day at school. I felt confident that he would be safe and that he would learn. As awful as it makes me sound I was actually relieved and happy for them to start kindergarten.

When Ben went to school it was the first break I had since he was born. Three hours a day of peace. I could spend time with Bobby. Read to him, color with him. I could actually take the time to empty my entire bladder when I had to go to the bathroom. Three glorious hours a day. It was just enough to make me start feeling sane again!!

On the first reading, I see the main event as a mother's worries about her child entering kindergarten. Recurrent images and thoughts are:

1. Fears - a) fears for her child, b) fears for his acceptance, and c) fears for his safety.
2. Advocacy and responsibility for her child expressed by - a) where she called, b) what she read, c) who she contacted, and d) what were the questions regarding the plans, the aides, the strategies.
3. Ambivalence - a) between her feelings of concern for her child's safety and well being and her excitement for "three hours of peace", b) around her guilt about feeling that way, "as awful as it makes me sound", and c) ambiguity between her trust and her mistrust of professionals and between her fear for her child and her relief for herself.
4. Battles against the system, for her child.

The most recurrent word was "I". I don't know if I would have noticed this frequency, had I not reread this sample of writing four times as suggested by Mauthner and Doucet (1998) and focused on the use of "I". Sally's frequent use of "I" made me ask myself questions about whether Sally feels she's alone and totally responsible in her cause, whether she feels only she can give her son what he needs. How much pressure does she feel to have so much responsibility on her shoulders? How much guilt does she feel when situations don't go as planned? How much does she feel she must do and how involved does she become - "I heard", "I decided", "I thought", "I called", "I felt." All of

these phrases suggest strong emotions and actions, always on what appears to be feelings of independence, responsibility and isolation.

During the second reading of the text, I put my own assumptions and views, that is, personal, political and theoretical, into my interpretation. As well, I included what I call my clinical/historical view, (i.e., prior knowledge and experience of the writer). It is hard to wait for the second reading to do this, as it is difficult not to do this during the first reading of the text. At first, it was more difficult excluding my knowledge of the writer, having worked clinically with herself and her family, than it was excluding my own feelings. I know a lot about Sally's character, about her feelings and her emotions of many of the stresses that she has been through with her son throughout his school career to date and about her relationship with her husband and how much involvement he had in the rearing and education of their children. This knowledge may have influenced some of the comments I made, for example with regard to her frequent use of "I." There are personal, political and theoretical elements that most definitely influence my interpretation.

My personal self relates to maternal feeling of the need to advocate, and of the need to nurture, to make the proper decisions, to battle anybody or any institution who is not prepared to give my child(ren) what they need and to the additional feelings of responsibilities that come with having a child with special needs. My political self is one who is very pro integration. I believe in including and accepting all children and all people for who they are. This probably influences the way I interpret some of her writing, particularly with regards to advocacy. My theoretical self probably considers areas of education when I am interpreting Sally's feelings. Further, my most recent theoretical

knowledge in the feminist research, in maternal thinking and research, and in advocacy come into play when interpreting this piece. I read into this document how prepared and how organized she is, how frustrated she must feel, how ambivalent she is over her many feelings. My personal, political, professional and theoretical self most definitely come into those areas of interpretation. I put a lot of focus on her contacting the Learning Disabilities Association, on her making the phone calls that were necessary, on her planning and organizing and troubleshooting, brainstorming and her trying to give her son the most successful and safe opportunity possible.

The third reading of the text is where I looked at the "I," the respondent as she speaks for herself. This comes out very clearly, as I mentioned in this text: "**I** didn't want my son to be labelled", "**I** didn't want him to be trouble", "**I** decided to meet the principle", "**I** had heard so much about the school", "Boy, was **I** misinformed", "**I** kept providing because **I** thought they were trying to help", "**I** found out from the hospital exactly what the school was up to, that is when **I** decided to educate myself on his rights to education", "**I** called the school two days before", "That is when **I** was told", "By this point **I** was no longer worried, **I** felt confident that he would be safe" and "**I** was actually relieved and happy for him to start Kindergarten."

The "I" strongly illustrates how Sally felt responsible, how she felt perhaps overwhelmed. Perhaps when I read it looking at the "I" I think of her being overwhelmed by the responsibility she had, by the confusion, by the ambivalence. Feelings of being alone also appear very clearly when looking at the "I." Certainly there are certain dynamics and dimensions to her writing which become much clearer when underlining

the "I", the frequency which is at least once in almost every sentence of the text. This was consistent in many of the pieces of writing the mothers wrote.

For my final reading I placed Sally and her story in the cultural context and within a social structure framework. During this reading, I focused on what the writing was saying, and how it fits with the facts of the school system, in particular the school system where her son was attending. She had "heard so much about the school system." This is a system that has a very strong reputation of accepting all children and of educating all children. The ambivalence of not getting what she wanted was seen in her expression of frequent concerns, that children such as her son often fall between the cracks, and are often misunderstood. She portrayed the lack of communication and co-ordination between the hospital and the school. These are some of the issues and questions that come out from the text that make me want to research and look further.

No matter what approach or approaches I used to analyze the texts, the themes and issues were recurrent and consistent. The concept of them trying to decide if they would accept Ben into the school is an example of a significant and painful issue and one seen frequently in many of the mothers' writings. The worry of whether the child will be accepted by a camp, a school, even by family and friends is pervasive and intense.

Sally was quite diligent about writing and submitting weekly journal entries. I present two here, one focusing on advocacy and problem solving, the other taking time to reflect on a positive moment. The first of Sally's journal entries was based on a reflection of a special moment.

Sally's Journal Entry (1)

One morning last week as I was patiently rushing Ben to get his coat and boots on, he looked at me with those sparkling brown eyes and devilish smile and said "Mom, do you know why God made you my mother?" And I said, "No Ben, Why did God make me your mother?" He said because you're the best mother in the whole wide world."

I chose to write this because I have had an extremely rough week with the teachers and powers that be at the school and school commission. I get so tired of everyone telling me all of Ben's bad points. They have no clue what this child is all about. He is the kindest, most caring, most loving, and most affectionate, most imaginative little boy you could ever meet. When he says things like this to me it gives me strength and the drive I need to fight to ensure his rights as a person are being met. After all, that's why God made me his mom!!

Even while reflecting on a happy moment, Sally mentions that "extremely rough week with the teachers and powers that be" and describes her hearing about all of Ben's negative characteristics. At the post-program interview, as Sally reread this journal entry, she communicated to me that she may not have remembered this moment had it not been written down. She expressed an appreciation for the documentation of this happy, positive memory and feelings. She appeared to focus on the positive aspects of this journal entry.

This second journal entry is based on Sally's reflections and feelings about her need to advocate and teach the teachers.

Sally's Journal Entry (2)

I can't predict the future. I can only deal with the "norms." I am doing everything physically and emotionally and financially possible to ensure Ben's success as an adult. But I have to do it one day at a time and I cannot do it alone. Part of that

> process is trying to ensure his success and happiness at school no matter what it takes. If he continues to find opposition at every level he will grow to hate school more and more and eventually drop out and it won't be because he is a failure but because you, the system, have failed him. Rid yourself of your preconceived notions of what a disability is or isn't. Read and educate yourselves and realize that Ben is not the only child out there with the symptoms he suffers from. Just because you have never had to deal with a child like him does not mean that they don't exist. Stop trying to turn his problems into what they are not and accept them for what they are. Learn the best way of dealing with children like Ben. Expand your horizons. Don't turn him into another statistic, full of anger and frustration like those in Columbine. Help me to help him before it gets that far. With all the therapy we are going through, Ben occasionally takes a few baby steps forward but you, the school and school committee are there to ensure that for each of these baby steps we achieve he gets to take three giant steps backwards.

Reading this piece, we can see problem solving and advocacy in motion. Sally is putting her goals on paper - trying to prepare Ben for success as an adult, keeping in mind the many obstacles and constraints. She breaks down the tasks, realizing that she cannot do it alone and that she must work at facilitating a process where school is more positive, successful and palatable for Ben. It is interesting to note that Sally suggests that the educators need to educate themselves.

Sally turns to writing to professionals, trying to advocate for all children with special needs and to educate the educators. This is a recurrent theme that I've noted both in the published autobiographies and in my field notes. It was a strong force behind the mothers wanting to publish their writings.

Sally changed from "me" to "you" without warning, almost like emotions identified and turned outward. This midway change in pronouns was seen in many of the

writings I collected. However, it was most often from third person to first when writing about, or to the child with special needs.

In this excerpt of Sally's writing, her anger turns to a plea for help and cooperation. Another theme which emerged in many of the writings was a need to be heard, understood, cared for and to be part of "the team" caring for their own child. This is consistent with the need to nurture the nurturer, nicely addressed by Featherstone (1999). It appears that Sally is expressing a need to be nurtured in her expression of loneliness and isolation and in her need for help so that she does not have to do this alone. The other mothers also reported feeling that they wanted to promote an understanding and awareness by others that as mothers, they are the "experts" on their own child.

The use of September 11th and Columbine was seen in many of the mother's writings. One of the greatest sources of their fears was the thought of their child growing up angry, aggressive and cruel.

Another writing activity was to write an angry letter. More than half of the participants wrote their angry letter to a professional. Sally chose to write to one of the first professionals that she saw when seeking help for her son Ben. She eloquently portrays her anger over the way their assessment was handled. It appears that mother blaming or at the very least feelings of blame and pointed fingers were rampant.

Letter for Professional

Dear Doctor …

You probably don't remember us. Just another hour-long evaluation. Just another couple of bickering parents who can't deal with their children.

I wonder, looking back on this first of many evaluations, if you were even hearing what we were saying. We were at our wits end. My husband working 10-12 hour days, trying desperately to get his business going, coming home every single day to chaos and destruction. Fighting, screaming, broken things he would have to replace. Accusations flying in my direction, on my abilities to mother my children. My self-esteem no longer existent. I was sure I was the worst mother alive. Although I did nothing all day except supervise my children, a 60-second visit to the bathroom could end up in stitches for a sibling.

When I read in your report that our son's problems "are due mainly to the hostilities between the parents," my initial impulse was to leave my husband. I realized he had some problems controlling his temper, but did not as yet understand why. I felt if my children were to have a chance in life, I had to remove them from this situation.

I thank God for helping me find what little strength I had at the time, and helping me realize what path to take. I decided to seek treatment for our son, regardless of your report, and lo and behold, although we will never be what could be considered as a 'normal' family, we have come a long way.

You did not see that our hostilities were not causing our son's problems. His problems were organic, and it was our not knowing anything about them that caused the hostilities. Had I not found the strength needed to follow through on treatment for him, and had I taken you at your word, God only knows where we would be today?

I am writing this in hopes that in future evaluations, you will take more time and find out where the problems really lie before passing judgment. Desperate people, such as myself when I first went to meet you, deserve better than an educated guess. You could have destroyed a whole family!

Sally expressed feelings that were consistent with Epston's (1994) suggestions that the letter writing process can be compelling and even empowering, and that only in rare cases are the letters not sent. Sally expressed her compelling and even somewhat empowering feelings. However, she did not send the letter. This may have been related that to the fact that she had no more contact with that professional and didn't even recall

the person's name, whereas the mothers who wrote to more familiar people were more compelled to send their letters. Sally still reported feeling good after writing the letter, and although she had no plans to send it to that particular professional, she did express feeling happy and excited about the idea of publishing her letter, so that perhaps other professionals could learn from and/or gain insight from her experiences. Adams (1990) suggests that unsent letters are marvelous tools to reach catharsis, completion and clarity. Sally expressed feeling good after putting it on paper and sharing feelings that had been with her for years. Sally's letter was received by the group with many "ah ha's" and similar stories/letters read by other group members. The obvious theme in the letter was anger; however, themes of disappointment, frustration and a need to advocate and make it better for themselves and for others, also came through. Sally and the other group members described their feelings of relief and satisfaction after writing the angry letters. A surge of drive and enthusiasm arose towards the objective of advocating for all children with special needs and their parents, educating professionals, supporting other families and helping them to advocate for themselves. Sally and the others expressed hopes of touching professionals, with their words.

Responses to weekly questionnaires and anecdotal comments.

When responding to the questionnaires given out at the end of each session, Sally explained that for some of the writing activities, she could not organize her thoughts. She believed that her thoughts were "unorganized" and that she was experiencing difficulties writing because she didn't want to face all the details and stresses of the day. When she would finally sit down at eleven p.m., she was afraid she may be facing "another

sleepless night." She wanted to "push her stresses way back" by watching TV or reading a novel to "take her brain on a vacation." It is interesting to view Sally's perception of how different reading and writing make her feel. Reading helps her give her brain a vacation, while writing forces her to "face the details."

Sally made the following anecdotal comments, after writing to music – a lullaby. Sally commented that she usually thinks while she's washing dishes, then she jots things down. She explained that it's hard to get her brain going. She talked about what she called the "issue of the week" as there's always something happening, new thoughts, new problems, etc. After writing about Ben's first day of school, Sally commented "mine sucks", once again – negative self judgment consistent with her poor self image. Sally commented on how, when writing a letter to another parent, she crossed things out. She also commented that she found it harder emotionally when she read what she wrote, than when she was actually writing it. She found the reading process different than the writing process. Many of the participants reported feeling more emotional, even crying more when reading what they wrote, than when actually writing it.

When the group was asked to write a poem or a critique on someone else's poem, Sally said she felt "panicky." She explained how she "froze on a poem." She wasn't able to choose a subject and she couldn't write on the subject. During one of the sessions, Sally talked about how she had been upset with an integration aid. She wrote pages of notes. She suggested that otherwise she would have "just stewed." She commented that she'll have to organize it. This appeared to be one of the major reasons written material was not handed in; the participants wanted to take it home and fix it and organize it and they never ended up bringing it back.

Post-project interview.

I asked Sally if she would participate in a one hour interview after the program had ended. We met for an hour which was not nearly enough time. It was then Sally, who suggested that she respond to the remaining questions in writing and after that we could meet again. She completed the questions in writing and then we met for close to two more hours. The process was excellent. Sally provided more focused and informative responses in writing and this proved to be an excellent springboard for a powerful discussion on many aspects of reading, writing and mothering. Sally explained her memories of why she initially joined the writing group. She had been attending a parenting group on Monday mornings, a non-structured, on-going support and oral discussion group, with an oral story-telling component.

When I described and proposed a new program which would be a therapeutic writing group, she recalled how I explained how the group would function and that eventually I was hoping to do this type of project as my thesis project for my PhD. Sally recalls that she agreed to participate, but was a little nervous about finding the time to do all the writing activities, a recurring theme and problem, probably related to the fact that this group of mothers (i.e., mothers of children with special needs), were already overwhelmed with time and energy commitments. Sally recalls thinking that she did not want to "disappoint Harriet" by not fully participating. This was a feeling that I had not previously been aware of. I tried to reflect on how this may have affected Sally and what it meant. I think this is related at least in her part to Sally's low self esteem and her desire to please others and to be approved by others. However, as a clinician and as a researcher,

I was concerned about the impact of these feelings and the relationships between client and therapist and/or between participant and researcher. Sally did not express any negative reactions related to this and I believe from Sally's recollections of that time, that as the program progressed, she felt more at ease. Sally felt that "any therapy was good therapy" and she had enjoyed all the groups she had attended thus far, therefore she looked forward to the benefits of this new program.

When recalling and discussing her objectives with regards to her emotional, practical and problem-solving needs, Sally explained that her objective for any kind of therapy was emotional support in dealing with her three children, each with their own set of special needs. She said that she has always come out of the groups feeling "refreshed and ready to face the always-challenging week ahead."

The writing group was on Monday mornings, as was the typical parenting support group, in which Sally had previously participated (i.e., consisting of oral story-telling and dialogue). Sally and many of the other mothers requested Monday as their first choice of days, since they felt that this fortified them for the challenges of the week ahead, including children, schools, work, homework, lunches, appointments etc.

In discussing whether Sally felt that she had accomplished any or all of her goals, she replied that although as she had feared, she did not always have the time to complete all the writing activities given as homework, she did benefit from the same refreshed feeling at the end of each session, that she had felt in the other program. She explained that this feeling may have been even more significant in the writing group, as she was always very good at talking about her children's problems and finding solutions for them, yet she had never been really good at discussing how she felt about having children with

special needs. This was an extremely important and enlightening comment, suggesting that the writing process elicited emotions that may not surface in the same way, or to the same degree, as in the oral storytelling process. The focus of her writing also appeared more personal and self reflecting than her spontaneous oral discourse.

Sally elaborated on this by explaining that she feels when you're in a group that gets together to discuss topics or feelings; you can pick and choose what you want to talk about and how far you want to go with it. She always tried to keep her personal feelings at bay and focused on what was best for the children. But when she was sitting quietly at home, writing journal entries and writing activities, she explained that she felt she had no choice but to write about her personal feelings, about everything. She explained as follows:

> I always, in the discussions, tried to focus on my children's problems and how to help them. In the writing group, although I did write about the children's problems, it focused also on how I felt about having children with special needs. This was something I never really dealt with before. It was a very liberating experience.

I believe that these comments, based on Sally's reflections, offer invaluable information on the benefits of writing as a therapy. Sally began by comparing the process of journal writing, while sitting quietly at home, to verbally discussing and storytelling with others. She commented on feeling "no choice" but to write about her personal feelings in full. The idea of feeling forced in the comfort and privacy of her home is interesting. Even more interesting is the fact that after writing her journal entries, she chose to share her reflections. Sally and the other participants were given choices; she

could have kept it to herself, given it to me to read on my own, read it to the group and/or pass it around to the other participants to read. She chose to read to the others and to give it to me to read and keep. In the end, she was more open than she had been during the more spontaneous, oral discussions groups.

The feelings that Sally describes above are consistent with what the literature suggests - that writing helps in identifying feelings and issues, by putting them on paper to problem solve and to find balance.

McGihon (1996) suggests this process can help individuals pinpoint the area of conflict in their lives and clarify complicated issues. Sally had already pinpointed her issues and how complicated they were. However, she later explained that the writing process helped her to resolve some feelings and clarify many issues. She found writing more private, even if she knew that people in her group would eventually be reading it, and she still finds it easier to write her feelings down rather than just standing up and talking about them. Once on paper, her thoughts became concrete and real.

In response to questions about the benefits/goals that Sally may have achieved that she hadn't planned on or expected, she reported that she never joins any kind of support group with particular goals in mind. Participating in groups had always made her feel better and that's really why she participated. She elaborated by explaining that the benefits achieved during the writing group process were all unexpected, but very liberating. She felt that she had lived experiences in this group that she had never achieved in any prior parenting groups. The other groups had similar participants (i.e., mothers of children with special needs), similar group size even same day, time and place and same facilitator. The only difference was that in the other groups, there was no

writing component. It's interesting to note that the writing part was one of the components Sally had feared, yet she later described it as the most liberating. I shared a similar experience, as did many others in the group.

When Sally was asked about what she enjoyed most overall in the writing group experiences, she responded that she seemed to have it all together when she was advocating for her children. She appeared to be self-confident and came off as knowing what she was doing. She explained that advocating for her children is a job with a specific goal: to ensure their rights as human beings. When it came to herself, she said she has a very low self-esteem. She has a lot of fears, one of which was her inability to speak in front of groups of people, although when advocating for her children, she explained that she quickly gets over that fear. When she had to read material that she had written, in front of people she did not know, she felt petrified. She was afraid that her writing would be inadequate and that people would judge her for what she had written or that they would laugh at her because what she had written was stupid. Nonetheless, she enjoyed the fact that she pushed herself to write and to read what she had written. She overcame her fear and although she felt that her writing was not as good as some of the other women, she did not feel judged nor did anyone laugh at her. Years ago she says she would have just not joined the group because her fear would have been so great it would have prevented her from even participating. Overcoming her fear of being judged and laughed at is what she reported enjoying the most.

I asked her what she enjoyed the least. She said she felt a pressure to not let me down because I was doing the project for school, and this was stressful for her if she was not being able to complete all the writing activities because of all the time restrictions at

home. Other than that, she really enjoyed all aspects of the writing group. Once again, although I was pleased that Sally was comfortable enough to express these feelings, this made me even more aware of the intense emotions so common in this population, particularly the overwhelming feeling of insecurities, responsibility and guilt.

I asked Sally whether there were any particular pieces of her own writing that affected her in a significant way, be it positive or negative? She said there was an writing activity where she had to write a poem. She said that she never in a million years thought she would have enough talent to actually write a poem. Although the writing activity was handed in three weeks late, and she did not read it in front of the group, she nevertheless did it, and felt so good about herself, that she couldn't even describe her intense elation. Unfortunately, she said that she can't find the poem, and is angry at herself for not keeping a copy of it. I found a copy of the poem after our meeting.

I then asked Sally if there was a piece of writing, written by someone else in the group that affected her in a significant way, and if yes, how and why? She responded that there was one woman who wrote very well. She couldn't remember exactly what was in her writings, but they were always so well written, hearing them could drive the other participants to tears. On the other hand, it did make Sally feel inadequate, that her writing was not very good and she hated having to read after that particular woman. She said that this was not the woman's fault and that she in no way wanted to make anyone feel this way. It was just her insecurities and her problem. Sally explained that she eventually overcame these insecure feelings.

The feeling of discomfort in reading what she wrote was consistent with what Dias *et al.* (1992) refers to as the process of "writing for ourselves", which can be

described as a situation in which a person writes primarily for themselves and knows that only they or perhaps a few selected individuals will read what is written. However, in Sally's case she appeared more concerned about exposing quality than content.

Sally appeared to be suffering from ambivalent feelings. On the one hand, was her desire to write to see her thoughts on paper for clarity and to facilitate the process of problem solving. On the other hand, she battled between the need to share her writing and the fear that her work was not good enough. She appears to be an open individual who is fairly comfortable with sharing her thoughts and emotions. It was with her writing ability that she felt insecure. She seems to be president of her children's fan club, but not even a member of her own. It would be interesting to explore this dichotomy, for example to evaluate, if this is related, at least in part, to her struggle with the good mother/bad mother dilemmas.

During the interview, I asked Sally whether any of the group discussions about writing in general and/or if the actual writing done in this workshop had a significant impact on her. She said that they always discussed everyone's written products and to her delight no one ever discussed the quality of the writing, only the content. This is what helped her overcome her shyness to read what she had written.

When I asked her about her overall experience in the group, she responded that she really enjoyed this group on a number of levels. First, because it gave her the opportunity to address her children's problems. Second, because it helped her overcome some of her own fears and to address some of her own feelings around having children with special needs.

I asked her if she felt she had changed after the workshop. She replied by saying:

> I have changed because I am more aware of my feelings. Although sometimes I feel a little selfish, I do take more time outs for myself realizing that my feelings and my well being are just as important as my children's if I am to continue advocating for them. It made me realize that my feelings are normal and that many women share the sadness and worry involved when having children with special needs.

This is very important. I was thrilled to see and hear that Sally had learned that her feelings are normal and that she's important. I was especially pleased to see that she had learned that in order to continue nurturing her children, she first had to nurture herself. This is consistent with the work of Featherstone (1999) suggesting that health care professionals pay more attention to the fact that mothers need to be nurtured.

Finally I asked Sally about what changes she would recommend to those organizing or participating in a writing group like this. She said that she couldn't really think of any changes that would benefit the group. She knows that time permitting, she would probably participate in a group like this again and now that her children are older, she would probably have more time to actually sit and do the writing activities to which she added "Wishful thinking!"

Sally reported that she enjoys listening to and talking about the stresses felt by the other members of the group and by herself. In her written response, she wrote about how listening to the writings of others helped her to learn that her feelings are "normal" and that there are people in the same boat or even more stressed than her. Feelings of stress and/or of being overwhelmed were a very prominent theme in Sally's writings. The "in

the same boat" feeling is characteristic of people in many support groups as well as a one of the benefits of bibliotherapy as well as of group therapy and support groups.

In responding to what she enjoyed least about the sessions, she responded, "Physically getting out of my comfortable chair and having to move (ha ha!.)" On the surface we see that she was probably trying to add humour to her responses. However, the feeling of comfort, of sitting back and letting it all out in a comfortable and "safe" environment could be observed and was often expressed in Sally's as well as in the other members' writings.

Chantal's Story

> My Love I want to tell you this. If I could I would hold your hand forever. I would hunt down your enemies be they in your mind or mine. I would hear what you can't tell me. And understand your unspoken words. If I could I would accept what you can't do and remember what you can do.

I started Chantal's story with an excerpt from her poem the *Dragon Slayers: or A Conversation* as this poem had a major impact on Chantal as well as on many of the other participants of the writing group and many others who have heard or read her poem. This poem became Chantal and the poem created a new identity for Chantal, "the author of that incredible poem." The poem visibly portrays the intense feelings of a mother whose child has been developing with special needs. Her deep, sensitive and conflicting feelings were illuminated in her poem, in a way that she felt she was never able to otherwise so effectively express. She was never even completely aware of, nor so deeply touched by this smorgasbord of thoughts and feelings. This poem as well as the process before,

during and after writing this poem will be discussed later in this chapter. Chantal's words are of hope and promises, promises of understanding, accepting and loving without boundaries. "If I could I would" suggests that love has no limits, but mothers do. Yet, mothers often feel they should do more, if only they could.

Chantal is the mother of two children. Her older child, Jonathan suffers from autism and her second son, Sam has atypical behaviours and some motor weaknesses. During this research project, Chantal had not yet been able to get a clear diagnosis. Subsequent to this project, Sam was diagnosed with Pervasive Development Disorder (P.D.D.). Chantal is very involved with her children and is constantly running to therapists and trying different programs. She also suffers from anxiety and a very low level of self-esteem, although during the program, her pride in her writing seemed to be associated with an increased level of pride and a higher level of self-esteem. Chantal experienced other areas of growth, which may as well have contributed to her growing self-esteem. During this same time, she began developing an interest and talent in drawing and painting.

Chantal and I knew each other prior to this program, as I had evaluated both of her sons. However, I knew nothing about her use of reading and writing, her heightened anxiety and low self-esteem, her desire to use her creativity or the wonderful use of words locked in her creative brain and the burning need to put these words on paper and to be heard.

Pre-project interview.

We started with the semi-structured interview. (See Appendix D) When I first asked Chantal about her early memories of writing, she described the following and commented that she believed the following was probably not really her earliest memory, but the one she most quickly and easily remembers. What she recalled was a memory of writing notes to her mother. Chantal remembers that she always wrote in French, because at the time they were living in France and communicated mostly in French. She recalled how they were always saying "I'm sorry" for what they did wrong as follows. "I am sorry for what I did wrong, can I please have 50 cents." She would then draw pictures and say "I love you." She said they played out this scene often. When I asked her if she used writing in her more recent life, she replied "not really." She recalled that she often wanted to try writing, but she found it to be very hard. When she wants to write, she explains that she always begins the process by writing in her head, but never thinks to put it down on paper. At the time of this initial interview, she explained how she had wanted to send her cousin an e-mail because at the time her cousin was pregnant. Chantal explained in an apologetic tone. "I am not even able to do that." She said she used writing to learn as when she tried to get information, she often made notes. It is interesting to note that Chantal responded that she didn't use writing much. Yet she spoke of list making and writing for learning, suggesting that she did, in fact, incorporate writing into her daily life. She appeared to be thinking of writing more as a means of creative expression. Chantal appeared to be using lists for learning and for problem solving, around dealing with mothering issues, particularly mothering a child with special needs. Her creative expression describing her feelings related to her child's special needs and dealing with

them, appear to have perhaps evolved out of her more basic writing. Chantal reported using writing to remember, to think, to make lists and to problem solve. She described how she used lists a lot. "I list everything I want to think about and how to organize it." She did not believe that she used writing to communicate, to feel, or to be creative. When asked why she decided to join the writing group she answered as follows:

> I want to write. I tried to get books on writing and things like that. I start but I find myself stopping myself as I am doing it. I started doing some exercises (i.e. writing exercises) and I really enjoyed it, but I just can't do everything. I can't paint and write and organize the house and everything. So I ended up having to let go of the writing and I figured that by joining the group for that time period it would be something that I am going to and participating in so I will do it (i.e. the writing) Being in a group is probably more motivating.

Her stress and her feelings of being overwhelmed with many competing chores and challenges can be felt through her words. When I asked Chantal about her expectations, objectives, hopes and fears, she replied that she was not really sure what her objectives were. Chantal said that when she was joining the group, she was not really sure about what the group would be doing. She hoped that she would benefit from the group process and from the other members. She was hoping to get a lot of writing done. Chantal explained how she finds it hard to write and to read her writing to other people. Before she started the program, she expected that the reading of her written works would be the hardest part for her. She explained that she would not want someone else to read her writing aloud, explaining "No, it is still me that wrote it."

During the interview, we discussed reading, particularly with regards to what and how Chantal relies on and/or benefits from reading. Chantal explained that her favourite reading material consisted of novels, non-fiction, science fiction and self-help. At the interview, she explained that she had been reading a Harlequin romance, which described a woman and, how the woman's mother was dealing with the problems that she was having. Chantal explained how the main character in the novel did not have friends and she described how the mother tried to comfort her daughter by suggesting that "we will just play by ourselves." Chantal related her feelings while reading the novel as follows: "I just related that to me and to Jonathan and how I am affecting him because he does not have friends and how I should be acting." Chantal elaborated on this by describing her feelings of guilt around the fact that she should have friends, so that she could be a good role model for her sons and so that she could provide friends for her children.

Chantal vividly expressed her feelings of guilt and her self perceptions of inadequacies, of not being able to give her children what she believed they so badly needed. Her feelings of responsibility for all aspects of her sons' development were very strong, as was her constant self judgment. Chantal's interpretations of the story and the effect it had on her, is an excellent example of how the reader's life, feelings, thoughts and perceptions interact with the author's writing to form an understanding and interpretation which may be unique to each reader. This is consistent with Manguel, who suggests that it is the reader who must give and decipher the meaning (Manguel, 1996). The reader takes from the reading different thoughts, feelings and messages, based on where they are at that particular place and time in their life. Many others may have read the same book and not even considered the mother's role in dealing with her daughters'

lack of friends, or for that matter, the part about the daughter not having friends may have been unimportant to other readers. Chantal explained that she does not like stories that are too dark and prefers the more pleasant, "happily ever after" type stories.

Writing selections.

For an angry letter, Chantal decided to write to her children's pediatrician, but not send it. Chantal had been angry with her children's doctor with regards to the care, or in her mind lack of care, her children were receiving. When recalling the experience of writing the angry letter, she described feeling both upset to realize those angry feelings were still there after so many years, and also feeling better, perhaps relieved after having put those angry feelings on paper and out of her mind. Chantal's honesty about feeling uncomfortable and even surprised by her residual anger, is consistent with the idea that we may only know how we feel only when we see our thoughts on paper. The following is the letter that Chantal wrote to her children's pediatrician.

Letter to Pediatrician

Dear Doctor,

I have a bone to pick with you. For years, I've been bringing my son to you and I am not satisfied with you. You have been a real jerk. You had the nerve to give me a lecture about trust, well how can I trust you. For every major problem I had with Jonathan I had to fight for him. At six months, he was delayed and you suggested therapy, but not right away. You wanted to wait another year, well why should I had to insist on immediate therapy. Then came our problems with his speech and you wanted to wait longer.

When I came to you in a panic because he was completely isolated, all you did was send me for a swimming course, and tell me I'm overprotective. Well, what the hell do you know what I am. You only see me once or twice a year for less than five minutes.

> I'm not finished with you. I had to call you back and tell you that I don't know how to help him and only then you sent me to the right person. For two years I begged you to help me with his eating problem. You knew there was a feeding clinic but you never sent us there, why? That's why they are there, you idiot. You only said he had behavior problems, but why can't you see that his behavior can be caused by something biological. You wouldn't even listen to the specialist who works at the feeding clinic. When I saw the neurologist and told him about Jonathan's problem. Two sentences doctor, two sentences and I get a phone call from the hospital for an appointment at the feeding clinic. It was a necessary step. You won't admit your mistakes.
>
> I can't forgive that we have struggled for a long time and after a certain age the problem is very hard to correct. That's all. I find myself wondering if you will dismiss more problems. Well you dismiss my concerns, I assure you, and if that is the case we are gone.

Many emotions can be seen in this letter, emotions that are so commonly expressed by mothers in similar situations. Chantal's anger is definitely apparent as in her frustration and her need to advocate. Also, her comments regarding her doctor calling her "overprotective" illustrate mother-blaming, judging mothers and professionals not listening to mothers.

Chantal expressed feeling embarrassed by her anger. However, the intensity of her anger, so many years later, illustrates her definite need to release this anger. Chantal reported feeling proud that she had put insults in her letter. She talked about incidents that "grip" her. She read her letter with an angry tone and was responded to by the others with encouragement and comments such as "go for it." Chantal recalled later that at the time she became so angry after writing and reading her letter, even angrier than she remembered feeling at the time which she wrote about. A month later she commented

that she found it very satisfying writing an angry letter and after the program looking back she said it helped her with her anger.

There are a number of interesting comments related to this letter. First, her language is clearly expressive of anger, disgust, frustration, disappointment and a need to let him know what he's done. Chantal is a sweet, pleasant, soft spoken woman who I believe would never have spoken the words in her letter to anyone, especially a professional. Yet, reading her own words to others appeared to bring her some pleasure and even satisfaction. Her comment "I had to insist on immediate therapy" was common in many of the writings of the participants of the group and in the popular literature (i.e., autobiographies). The two words "I" and "insist" are particularly compelling. "I" highlights the mothers' need to advocate, take charge, handle it all, consistent with Sally's kindergarten narrative. "Insist" is one word which portrays the fight the many mothers of children with special needs are forced to use as they battle, insist, beg and demand that their children be diagnosed, treated, educated, respected, included, etc. Another interesting comment was about trust "you had the nerve to give me a lecture about trust, well how can I trust you." Chantal felt this was a lecture, one she wasn't prepared to listen to, as feelings of trust and/or respect, are feelings that a professional must earn, not expect. Fortunately, in recent years efforts are being made to analyze the parent-professional relationship. However, there's still a long and perhaps windy road ahead. These feelings are related in the work of Seligman and Darling (1997) and certainly illustrate the impact remaining from the long history of relationships and attitudes between mothers and physicians. "Tell me, I'm overprotective" is consistent with mother blaming. Chantal's comment that Jonathan's behaviour was caused by

something biological is indicative of the changes in our understanding that autism and many other disorders have biological roots, thus removing some of the guilt and blame of the past, for example the term "Refrigerated Mothers" (Kanner 1943). Yet mothers still feel guilty when their children behave badly and are still blamed for their children's bad behaviours, their bad marks in school, etc. The end of her entry is "I can't forgive you" and "Well you dismiss my concerns, I assure you, and if that is the case we are gone." Chantal blames her doctor for not listening, for not doing what he was supposed to do, for allowing precious time (early intervention) to pass. This blame is a recurrent theme in the other mothers' writings as well. The blame is most often centered around: "you didn't listen", "you didn't help", "we wasted time." Her last line is sort of a threat, yet it illustrates Chantal's desire to take control of herself and her children, to advocate for her children and to assert herself. This letter gave her a chance to put these long held feelings on paper and then share these words with others. Her calling her children's doctor "a jerk" and "an idiot", received responses from the others of "ya" and "ahh," and with validation and cheers. She felt surprised and uncomfortable that these angry feelings were still there, yet she felt good to get them out in the open.

Chantal's first piece of writing was her poem, the *Dragon Slayers*. The poem was the focus of much writing and discussion. Her own reaction to her writing the *Dragon Slayers* was mostly one of pleasure, maybe a bit of surprise, and lots of pride (internally, and in response to the group's reactions). However she also expressed some feelings of embarrassment related to the language.

The Dragon Slayers (or A Conversation)

I will cut out your heart and feed it to the wolves
Who are you? Who did this to us?
I seek answers to my questions and question all these answers.
Who did this to us? Who has brought you to my door?
I will find you and hunt you down
Give me back what you have taken from me. It is mine.
Oh Jonathan How sweet you were when I first held you
For you I would slay this dragon and bring him to his knees
My love I want to tell you this
If I could I would hold your hand forever
I would hunt down your enemies be they in your mind or mine
I would hear what you can't tell me
And understand your unspoken words.
If I could I would accept what you can't do and remember what you can do
I want to reach your mind, your spirit and touch the heart of you
I want to slide my hand into your brain
And heal the broken matter
I want to cut away my fears for you.
So tender is my love for you, so fierce is my devotion
And that will never change no matter who you are
Yes, I will slay this dragon and
I will fight for you, even fight with you.
Mom, I want to tell you something too
If I could, I would hear what you say
And do what you ask.
I would speak what I think to you and to them
And know what I want to say
If I could, I would know who you are and be what you want
I would talk with you and walk with you
I would laugh in all the right places
And say all the right phrases
If I could, I would want to have friends
And play the right games.
But, now that isn't so.
Don't be sad for me
We have begun an adventure together.
I am happy right now, remember that
Sometimes I won't be, sometimes I will hurt
But I know you will be there to love me
And slay the dragons in my path
My true friends are Daddy, Sam and you.

The group was taken by her poem, as was Chantal herself. Initially, when she wrote poetry, she was much more eloquent and expressive than she was in her speech or any of her other writing efforts, although with time, she appeared to express herself better in many different modes (i.e. speaking and other forms of writing). The impact of the *Dragon Slayers* on Chantal was gradual, but profound. She was proud of her poem and it helped her to feel better about herself. At a case conference meeting for her son Jonathan at his school, with Chantal's permission, I brought the poem and I asked the teachers to read it. I then told them who wrote it. Their response was exciting to see. Their attitudes suddenly changed. They appeared to be softer, as a new level of understanding and respect surfaced. Chantal told me at that time that she was very proud and pleased with the fact that I had given the teachers her poem. She was very pleased by their initial reactions. Although, she did not feel any lasting effects.

The poem certainly portrays the anger and the need to advocate, to fight for and promote the child with special needs. The emotions expressed are anger, fear, love and protection. A mother's love and desire to do anything and everything for one's child is certainly expressed in this poem. Chantal's style of changing from third person (talking about her son) to first person (speaking in the voice of her son), was used by a number of the participants. There appeared to be a number of reasons for this. The prime reason appeared to be a need to understand what the child is feeling and a need to be the child's voice, to explain their behaviours and their disorder. Chantal explained that before even writing the poem, she wanted to portray a conversation.

She explained feeling a little embarrassed by The *Dragon Slayers* because she felt it was violent. But she explained that everyone loved the passion. "Because it is

passionate, who would not do that for their child?" Chantal was referring to the part about the grey matter, sliding her hand in and fixing his brain. She says that is what you would do for a child:

> That is what people love and they will say that is exactly what they feel. I wish I could get in there and do that. What mother wouldn't? What mother would not cut out a heart for her child? I was just saying it for all of us.

Chantal's heard all this and yet she still felt embarrassed by the intensity of her thoughts and the imagery of her emotions. It is almost as if it's okay to feel these emotions, yet not okay to express them. We discussed why Chantal felt embarrassed by the *Dragon Slayers*. I had been totally unaware of this emotion and with a surprised tone, I'm sure, asked her why. She responded "it does because it is very....like look at the way it starts...you know...and I added that at the end...I added the I will cut" I asked what exactly embarrassed her, she responded that she felt it was sort of violent. She added however, that it is the violence and the passion that everyone loves. I agree with Chantal about the passion and about the intense emotions mothers have and how far a mother would go to save their child from the dragons. Not all mothers feel that way, but Chantal's convictions are strong and her voice and feelings shine through. Yet, she feels embarrassed by those strong feelings, perhaps believing that a mother should be sweet and gentle, kind and nurturing, even while she believes that these feelings are natural for any mother. These ambivalent feelings are perhaps different than the love/hate ambivalence described by Parker (1997) and others. They are however, another example of the many ambivalent, conflicting and confusing feelings that these mothers must deal with.

Chantal ended this little soliloquy with a quote suggesting the gratitude that the others expressed to her for being their voice. A theme that came out during the sessions was a need to be heard, to give a voice to mothers of children with special needs. The writing did this for many of the participants. They all expressed a desire to publish a collection, not for fame (they would be anonymous) and not for monetary gain (some of the proceeds would go to funding programs) but in the hope that the writing would offer support to other mothers. There was an almost burning desire to have their "voices" read by professionals, family, and friends, so that maybe they could understand "even just a little bit better."

One of the activities during the writing workshop was "ink shedding" that is, written responses to the writing of others. The *Dragon Slayers* was a poem that many of the members chose to respond to.

One mother wrote …

I love to read and write. I will even read poetry but I dislike writing poems. I have chosen instead to write about how I felt when I read another mother's poem, called "The Dragon Slayers." When I read this poem, I felt like I could have written it. This hits home about how I feel about my eldest boy. I wish I could always be there, especially when kids can be cruel to one who is different.

Another mother wrote …

As I read the poem entitled "The Dragon Slayers", I am overwhelmed with emotions. I feel the anger expressed by the author as she refers to her child's disability. I too hate that "the monster" who has taken over the sweet, precious child I so adored the day she was born. As I read on, I began to feel sadness and helplessness conveyed in the poem. I will never forget the immense love and joy I felt the day my daughter came into this world. Little did I know that those wonderful emotions would be replaced with emotions of confusion, desperation, and profound sadness.

It is compelling to see how this poem affected the others. They could relate, they understood and it appeared to act as a prompt to their memories of similar feelings.

When I asked Chantal about the impact of the other people's writing on her, she responded that there was nothing that affected her negatively or positively. She did feel affected by the reactions of the others to her writing of the *Dragon Slayers* as her poem received many reactions from other people. She commented on how when she wrote it she didn't even cry. "You know like a big bubble inside. I don't know. This is a hard one to answer. I just got more confident." When I asked her if she felt that she had become more confident when writing the poem or by the reaction of others she replied "both."

One of the exercises that the participants were given was to find something of the child's and to use it as a memory prompt. It was suggested that they focus on the prompt and write. Chantal brought a little bottle to our group, with a smile and a sense of pride and security. Chantal placed the bottle on the round table in the center of our informal circle and she began reading her words-providing a story for the prompt on the table. Chantal read the following.

An Object As A Prompt

When I look at his baby bottle my thoughts are filled with Jonathan. It is very special to me more so than I thought. A few weeks ago I was cleaning out my kitchen closet; I found about ten baby bottles, big ones. I readily put them in a bag which was to go to the Salvation Army. Then I saw the small one in the back of the closet. I picked it up. I was instantly transported back to Jonathan's birth. His new-born days. It was a time of great joy for me. I was so intensely happy with my baby boy. Life was full of possibilities. I became overwhelmed with those memories and then I became sad because those days everything was perfect and now it's not. I know better. I picked up the bottle and put it in the bag. What would I need it for anymore? Both boys are over that stage.

> I walked away but my heart was still in the past in those sweet moments of innocence in both of us. I turned back and took out the bottle and decided to keep it. The kids found it and thought it was funny to drink from it. I thought that it was wonderful that this bottle came back to life for me and them. I plan to keep this bottle and one day give it to my son when he has his baby. Even now I look at this bottle I feel love.

When I read and re-read this passage I am struck by a number of thoughts. First, I think about how powerful a memory prompt can be. This bottle brought Chantal back to a time of happiness and hope. "Life was full of possibilities." The diagnosis of a child with special needs often shatters a mother's hopes and dreams and happy times. Hopeful thoughts may be replaced with sadness, and fears for the child's future. Chantal expresses this change in emotions when she writes "I became overwhelmed with these memories and then I became sad because those days everything was perfect and now it's not." Chantal's words express a very common experience, felt by many, if not most, parents of children with special needs. These feelings were stirred up by a small plastic baby bottle.

This was a theme I noted frequently, it was very similar to an experience I myself had felt. It's the idea of before and after a significant event in one's life. It's amazing how a picture or an object can bring alive such compelling feelings of "that was before…I was happy then." This is a wonderful example of how memory work can offer new perspectives on thoughts and feelings, even on memories.

Anecdotal comments.

Some of Chantal's anecdotal comments recorded during the sessions revealed the following:

When writing to music, a lullaby, she said she was almost in tears. She felt there was no purpose, but it was nice. She was hesitant to read what she had written and she kept repeating "it's sappy, it's so sappy." She never gave in what she had written, and I never saw what she wrote however, I felt that she was moved by the music, yet unhappy with the product. I don't know if her discontent was related to content, style, the words that she wrote or the feelings and thoughts she portrayed.

During the writing activities of describing the first day of kindergarten, Chantal commented that when writing about Jonathan's first day of school, there was so much to write, she couldn't stop. She didn't hand this product in. She commented that she could have gone on and on.

During one of the sessions, Chantal began describing how listening to motivational audiotapes helped her. The examples she used to explain the changes that she observed in herself were: changing negative comments to positive comments; changing the words that she uses; using more "powerful-talk," for example, instead of saying "spend time", she started using the phrase "invest time". She commented on how she planned to use this power talk in her child Jonathan's parent-teacher interviews. This was an excellent example of not only powerful words, but an illustration of the power of words. Spending time sounds like a chore, of giving time away, whereas investing time, sounds more positive and beneficial. By suggesting that she planned to use this approach at her next parent-teacher interviews, I believe that she was illustrating the importance of the impact of one's choice of words. Her plan to choose her words and to think and speak positively at the next parent-teacher interview, is an indication of the fear and conflict associated with these meetings for many mothers of children with special needs. This

illustrated once again mother's burning desire to improve communication between parent and teacher. Chantal was illustrating the stress she has often experienced around parent-teacher meetings and her need to find a more positive approach, with the hope of a more positive outcome. Difficulties in parent-teacher communication and collaboration were a common theme in this group as well as in most of the popular literature.

When talking about her writing, Chantal commented that her work will "probably never get published" but that she feels she must do the writing for her own pleasure. During one session, she described how when she was finished writing a piece, she reflected upon it. She often said to herself that she "wasn't really organized" but that after she would "fix it up." Once when talking to the others she commented that she had forgotten her thoughts to which Wanda responded "you should have written it down." These comments, often made partly in jest, illustrated their beliefs in the importance of writing.

Post-project interview.

Following the program, Chantal and I met for another semi structured interview and discussion. From the onset of the interview, it was clearly evident that there was a major change in Chantal's entire demeanor. She appeared more relaxed, interactive and self-assured. We began some memory work focusing around Chantal's use of reading and writing before the writing group and why she had initially decided to join the writing group. This interview with Chantal was very enlightening and revealing. It was an excellent example of memory work and of participant as co-researcher. During the interview or discussion/ working meeting, Chantal frequently referred to her early

emotions. When asked how the writings of others affected her, she shyly responded "I think I was really numb back there." She explained that even during the group sessions, she experienced those numb feelings. She described herself, at the time, as more self-centered:

> To be honest, I was thinking more of myself than the other people. I don't think I had a reaction to them, I think I was too absorbed in myself, in my pain, in my feelings, to think about other people.

These feelings of numbness, pain and self absorption are very common in the initial stages. Listening to Chantal, I could imagine and actually feel her pain and sadness, as her expression of her earlier thoughts brought us both back to that very specific time and place. Listening to Chantal and then transcribing her words, helped me to better understand some of the difficulties I, as a researcher, had been faced with when I was organizing and facilitating the writing group, and to better understand the many possible reasons for poor attendance and uneven participation. I had realized sometime during the program that the nature of the group (i.e., mothers of children with special needs), contributed to various obstacles such as children getting sick, no babysitters, medical and other emergencies (i.e., a call from school with the announcement of a suspension), which interfered with attendance and with productivity. What I hadn't thought about before listening to Chantal's recollection and reviewing the literature (Seligman and Darling, 1997) was that the mindset of each individual and the variations and oscillation of "the place" they were in, differed between individuals and within individuals, between sessions.

Questions such as how one can listen or read the stories of others, if they're heavily into denial, anger, or guilt and how their stage will influence how they respond to the writing of others, became most interesting. Chantal reported that there were no writing experiences that were actually negative or produced negative results or reactions.

Chantal explained that initially she came to the writing group looking for a form of therapy and an opportunity to be creative. She enjoyed the support and the social part, "Just got me out of the house to do something else and I felt good. I felt that I was accomplishing something." When discussing what she felt she had accomplished, she explained that she initially did not have any real goals. She did not have any expectations. At that time, she was finding it hard to write, "You know it was interesting for me as to why I was having a hard time writing something. But I didn't really have any goals, mind you." She never figured out why she was having a hard time. She wondered about it, but never figured out the reason. She did not have any real expectations for the program, but she did achieve some benefits that she was not expecting. When she wrote, particularly the poem the *Dragon Slayers* she responded "It made me feel like wow, I can do something like that." She explained how she wrote when she was younger and when she was in high school she would write poems all the time. "But you know with time I just stopped. If I apply myself, if I put my energy into it, I think I can do it. But I am not." Chantal explained that she knew she had the ability to write, she just didn't seem to have the opportunity, confidence and conviction to write. It is interesting to note that in the beginning, at the interview prior to the writing program, Chantal had not mentioned anything about her prior writing of poems. She appeared to not remember. However, subsequent to the program, positive memories of her writing seemed to emerge. It seems

that Chantal forgot her earlier, positive experiences with writing. It's as if the experience of writing the *Dragon Slayers* served as a prompt to retrieve the memories of her earlier writing experiences. She benefited from the positive memories of her earlier successes with writing, while experiencing her more recent positive writing experiences. Chantal explained that in the program:

> It showed me that I can write and get my feelings out if I want to. But for me it takes energy. It takes energy and I do not know how to say it. It is not actually to get going. I always find even when painting, if it is there, it is there. I leave it as forgotten. If I start then I will be able to continue and I find that it is the same with writing. If I start, I will be able to continue, but it is just getting myself initially going. But it did prove to me that I am able. I am still able to produce something that is nice, that is emotional. I like when we were together (i.e. writing). We did not do that too much but I liked when we did that. I enjoyed writing to the music a lot I realized this was a very important part of the writing group, the actual sitting down and writing together. When I wrote the poem The *Dragon Slayers* I had an idea. It is not that I just sat down and wrote it. I wanted it to be a conversation. I wanted it to be two people talking to each other. It is not like, I don't know. It just made me feel good. I had an idea. It was not just sit down and write a poem. It was a structured idea.

After the program, Chantal revisited the topic of reading the stories written by mothers raising children with special needs. She explained how when she first responded to this question, it was during a very difficult time for her; she was struggling with two

children with special needs, her own emotions and other issues, for example, interfering extended family members. She described her feelings when reading *Let me hear your voice*, by Catherine Maurice (1994), a mother of three children, two who have been diagnosed with autism. Her response was "I had enough to deal with at the time with my own children's problems; I couldn't deal with her problems (i.e., Maurice) as well." Chantal later commented that earlier was a difficult time for her and that perhaps at a time after the program, she may have been more ready to read a book like the one written by Ms. Maurice. Chantal's first comments are consistent with the literature suggesting that different people choose and benefit from different types of reading (i.e., some want self help, others like tragedy, still others want comedy, love stories, etc.) (Gold,, 1990).

Chantal's later comments provided links between the literature on bibliotherapy and the literature on stages of mourning. That is, she was at a different stage prior to the program than she was after the program. She explained how she subsequently realized that she might benefit from this type of reading, where it felt harmful to her earlier on.

This discussion about different needs, likes, and dislikes and objectives related to different stages of mourning, when it comes to the uses of bibliotherapy was most enlightening. This made me think about the importance of really listening to the person I am dealing with, whether in clinical or research practice, and understanding where they are (i.e., at what stages). This understanding is critical to answering research questions and to recommending tools for bibliotherapy and/or narrative therapy, for individuals and or for groups.

All of the mothers at different times were either numb, self absorbed and/or more often so busy just dealing with life, that coming to the sessions and even more so writing

in between, was often an extra demand that for some, was overwhelming. For Chantal, the benefits of the support and the hope of fulfilling some of her creative dreams, outweighed the discomfort of these demands. As well, her first piece was the *Dragon Slayers*, which was received exceptionally well by the others and by Chantal herself. This perhaps helped her feel less pressured to write after her successful venture. It is interesting to note that when Chantal recalls that period of time, she tells the story of a woman who was numb, self-absorbed and not really part of the group yet, my notes reveal that although her attendance was not perfect, it was one of the most consistent, her writing activities were completed and often handed in, and her participation, reviewed through anecdotal notes and my memories, suggest that she was in tune to the others and to the discussions which ensued. This inconsistency between Chantal's memories of her internal experiences and the written records (i.e., her writings and comments at the time), are consistent with memory research suggesting that memories of emotions and perceptions may be different than what appears to be reality, yet these memories are true to the individual remembering them. It is how the individual recalls these memories which is their truth and which is what I believe to be the information that I am interested in. That is, how a woman who is mothering a child with special needs remembers the situations, experiences and feelings, that she goes through, at the various stages of her child's life and her own. The opportunity to read one's writing years later and compare stored memories to what is written on paper is exciting. The memories elicited by reading one's own writing, at a later date is very interesting as well and will be discussed later in this section. For Chantal, the memories she discusses are those of feeling numb, self-

involved and perhaps ineffective. These are consistent with the literature on stages of mourning, (i.e., stage one, denial).

The only part of the data which I did not have from Chantal was the weekly questionnaire to be completed after the sessions. This was consistently the part least often completed by all the participants. This may be at least in part due to the fact that the participants usually became very involved in the discussions, often going past the end of the time scheduled, they then found themselves running out, promising to bring it next time. They all lead very hectic, demanding lives, and therefore their promise to bring the questionnaire responses next time was a promise which was usually quickly forgotten in the business of life. After that, their feelings about the sessions may have been forgotten. By the next session we were on a new adventure in writing. Chantal remembered this as being the reason she didn't hand in completed questionnaires. I wondered as well, if the questionnaires, being a more probing and directive approach, may have been intimidating and/or frustrating.

In continuing to remember and discuss the workshops, Chantal recalled that overall she really enjoyed the program. When asked what she enjoyed she responded "I like to hear what people have gone through. I like to know that I am not the only one going through something like that." She explained that she liked hearing what others had experienced:

> What did you do, how did you solve, that stuff came up as well. It wasn't just the writing. Your emotions, there was a lot of sharing of real life with your children and that was important to me. You were able to share and they were responding to that as well. It was good feedback.

Once again, it is interesting to note some of the conflicting emotions that Chantal was recalling and expressing. She recalled feeling numb and self absorbed. She expressed how she was not able to deal with the problems that an author (i.e., Catherine Maurice) was describing in her autobiography. Chantal explained she was having enough problems dealing with her own problems. Yet, at the same time, she recalled the experiences of the group as positive and supportive, as she expressed the benefits of this supportive setting, and of hearing the stories and the experiences of others. These discrepancies may be in part related to timing. The reading of the book came at a much earlier time in her life as the mother of children with special needs. As well, her feelings related to the program may have differed from the beginning of the workshops (i.e., the first pilot session), to the the last session of the project. The writing workshop started a few years after Jonathan's diagnosis. The effects, positive and negative, can often be delayed. This again illustrates the effects of time and stages of mourning on the feelings, attitudes and behaviours of mothers of children with special needs. The more I talked with Chantal, the more we remembered together, while we reviewed and shared the data (written works, anecdotal notes, and interview transcripts), the more I appreciated the value of descriptive research in understanding complex human emotions and experiences, and the importance of including the participant as part of the research team. The more I reviewed my notes, while I continued dialoguing with Chantal, the more I learned about her feelings, memories, and emotions. The more I wrote and rewrote these discussions and writings, the more I kept seeing the similarities between my participants and my own experiences, the experiences of my (psychologist) clients, and the similarities with the literature both

peer reviewed and popular literature. These processes of reading and rereading, writing and re-writing, are consistent with the suggestions of Van Manen (1990).

When I asked Chantal if she thought that she had experienced any changes in herself related to the program, she responded that she didn't know. I respected her answer and began to wonder why I asked it in the first place. I was not looking to evaluate the program and I know that so much has gone on in Chantal's life and the lives of her children during this time; it would be ridiculous to try and identify what "affected" what. However, observing the process has been most interesting. That is, I feel fortunate in having had the opportunity to observe Chantal as she developed. She looks and acts more assertive, more self assured and more able. However, I learned from Chantal's memories of the pre and early program time that her looks and actions may be deceiving. Maybe her "I don't know" was a response suggesting that she can't self judge, she doesn't know if she's changed. I decided as I was writing this that I needed to ask her generally, how she thinks she has changed over the last couple of years. Her response was that she had become "more of a basket case." Her reactions became more physical and she could feel the anxiety. She wasn't yet at the stage of acceptance. She accepts it more now.

When discussing what was good or bad within the program and what I could change if I ever ran such a group in the future, Chantal's responded as follows:

> I liked when we wrote together. I felt I would do it at the last minute, I didn't like that. I meant that I was pushing myself and that I may not have gotten as much out of it as I should have. I think it is in a way...I mean you can't really make people write it earlier and take their time, but I think

> that was important. Not just leave it like that at totally the end, oh I have to get it done because we are coming tomorrow.

I asked Chantal if she felt that having the group forced her to at least sit down and write. I chose to ask her that question as she had often commented on her difficulty in following through on her dreams to write. Yet she had produced nicely during our sessions together. Her response was, "that is what is happening now. I don't look at my books again," she expanded on her thought as follows:

> The people who always write, they just have this need. If I have this need, I am going to think it but I am not going to write it. I will write it in my head, but it is never going to get to the paper, and I remembered doing that when we were doing the group. I am going to write this and this and I would say it to myself but I never actually got it on paper.

I could relate to these experiences as I too think and compose in my head and far too often don't get it down on paper. During my doctoral program I wrote more as I tried to experience the experiences with my participants. I kept notes of my thoughts. However, I too still had many thoughts that never made it to paper. So with this understanding I asked Chantal if she felt slowed down by writing. She responded that she felt this did slow her down. She explained as follows:

> I didn't go to the computer because I thought it takes too much energy. Like grabbing paper and a pencil is easier for me and then I lose the thought. This is what I want to write and then I get distracted and you know what I was writing at that moment I would forget what I wanted to

say. When you say it to yourself and you are thinking, oh this is what I want to write technically it is writing, but not with paper.

Chantal said using a computer, she would probably write it first and then transfer it. She could then make the changes. This is an interesting description of the process of thinking, reflecting and writing which I would like to explore further at some time.

When I asked Chantal about her opinions on the writings of the other participants and how they affected her, she responded that she could not critique them, particularly with regards to style, as she did not feel she had a right to critique their style. She believed she may feel more comfortable commenting on and/or critiquing the work of others with regards to the content. She described that what she was looking for in the other participants' written work was truthfulness, and bringing your own self into what you are writing and feeling. What she seemed to be looking for is a feeling of support and common emotions. This is consistent with the research on the belief of support and of formal support groups.

When I asked Chantal about her least positive writing experience, she quickly responded that it was the writing activity where they were asked to write an angry letter. She found that experience difficult as she realized she was "still very angry." She explained that it "just brought out my anger again." At the same time, she described how she felt better afterwards. She explained "I felt better actually when it was finished and I read it...I mean it showed how angry I was." I remember Chantal's smile and what appeared to be a sense of satisfaction. It's interesting that Chantal recalls that satisfying feeling, yet, she explained how she didn't like this particular writing activity as it showed her that she still had anger. This is an example of where writing can sometimes uncover

feelings in the writer that the writer herself may not have been aware of. Chantal was not comfortable with her angry feelings. She commented on this discomfort, even embarrassment, with regards to her angry letter and with regards to the anger and violence she saw in her imagery of the *Dragon Slayers*.

After discussing Chantal's feelings of embarrassment when reading her own violent thoughts and the realization that she was just brave enough to verbalize the natural feeling of most mothers, who would do anything to protect their children, Chantal shared a story with me. She spoke of how one year before, it had been Jonathon's first communion and the parents were asked if they wanted to make their own confession. She had wanted to, but felt "too chicken."

Chantal explained that this year, her younger son Sam participated in his first communion:

> I went and I told him, you know, I am angry, I don't remember, like he goes, what do you have to confess? I told him I am jealous of my friend who does not have any "bad kids", etc...And he told me, your penance is you have to talk to God and tell him how angry you are.

She seemed surprised as she described the end of this experience. She explained, "He didn't give me anything like 12 Hail Mary's." Chantal explained how she felt amazed that the priest was telling her that not only was it O.K. to be angry at God, but that she must express her anger towards God. She said "I have never sat down and asked God why did you do this to me? I did it a couple of times, but I felt like a bad Catholic." I found this story very interesting. First of all, she ends it with the fear of being a "bad Catholic." I began to wonder if this held similarities to the "Bad Mother" theme. That is,

do negative feelings make us "bad"? I was impressed by her description of the priest's response, not only did he abstain from giving Chantal a sort of punishment for what she believed was a sin (i.e. being angry at God), rather he gave her permission to be angry, probably understanding the necessity for Chantal to express her anger and feel validated.

The writing program was over, but I still suggested that she draft an angry letter to God. She accepted this new writing challenge enthusiastically.

Wanda's Story

> My secondary role, which seems to take up 90% of my time and energy, is that of mother to 4, aged 18, 15, 9 and 6. I love them so much it's scary. I'm proud of their struggles more than their accomplishments and they also drive me insane!! I have realized one very important thing about myself in the last year and a half and that is my ability to cope with the twists and ugly turns of life... I have worked relentlessly to help my son become all that he could be. We have been followed by occupational and physical therapists, speech/language pathologists and we have nurtured his capacity to grow and learn. I have spent thousands of dollars paying specialists who could help him master the tasks we normally learn instinctively. I handed my carefully monitored child over to the public school system and watched from the sidelines.

Wanda is the mother of four children. She is in an intact marriage and all of her children are from the same marriage. One of her children, Peter was born with a rare genetic disorder, which causes some changes in physical features, delayed development

and a significant number of atypical and aggressive behaviours. She has been very involved in Peter's care, as she has been in raising all her children. She has developed a career as an Integration Aide in a special education program. She is constantly reading and researching for her own interest, while learning and trying to help other parents of children with special needs. She brought to the group her varied perspectives, her wit and her ideas.

I began the chapter about Wanda with selected portions of her written introduction. My goal in selecting this portion was to attempt to highlight her perspectives of herself as a mother, her ability to deal with challenges, her feelings towards her responsibility to stimulate and educate her developing child, and finally her feelings towards the parent/school relationship (i.e., "handing him over"). Wanda, like Sally, begins her introduction by describing herself in relation to her family (i.e., a wife and mother). Wanda's introduction differs from others, in that she spends considerable time discussing her strengths and weaknesses, the pros and cons of her being. Her written monologue is laden with the ambiguities so often attributed to mothers in their self perceptions and in society's perceptions of women and more specifically mothers.

Wanda describes herself as creative, but not original, intelligent, but lacking memory, insight, organization and verbal expression. She feels good, but not good enough. She feels she needs to improve, but is maybe not a "bad sort." Wanda's comments about not staying with science as she cared about people more than molecules, makes me wonder if she sees a strict dichotomy between scientists and compassion. She states that her increased knowledge is based on her reading. Wanda describes in positive terms her friendship with three other women. She ends her introduction of herself by

describing how she "relentlessly" worked to help her son become all he could be and then "handed him over to the public school system and watched from the sidelines." This final statement is sort of thrown in at the end, not really following the style that preceded it. Yet, the thought is powerful, packed with underlying emotions and perhaps messages, maybe even a cry for help and/or reassurance. This feeling of "handing" her child over to the school, was expressed in the writing of some of the other mothers, particularly when they wrote about their child's first day of kindergarten. The idea of new emotions or old ones revisited, around the time the child enters school has been discussed in the literature (Seligman and Darling, 1997). This is an emotional time for all mothers, and even more so when the child has special needs. These comments however, also point to the perception that home and school are not truly working together. This was a very intense, emotion packed theme which emerged frequently and intensely in the writings of many of the mothers.

Pre-project interview.

Wanda began her participation in this project with an initial semi-structured interview. During the interview, she explained that her early recollections of writing were situated around school. She recalls that she was "apparently not a good writer." She recalls the time when she attended a French language school, where she wrote with "Anglicism and poor grammar." She described feeling that in high school, her English teachers did not seem impressed with her point of view or with her creative instincts. Writing was not a pastime that she pursued.

Wanda explains that until this point in her life, most of her writing had been for "functional reasons - thank you notes, condolences, and newsy correspondence." During her university years, Wanda recalls how she spent many summers in Europe. She began writing in a journal so that she could "relive" her experiences and "think them through." Both the ideas of reliving experiences and thinking things through once they are written are consistent with the literature. Wanda went on to recall how when her first child was born, she did not want to forget all the new things that were happening, so she kept a journal.

When discussing or writing about her own uses for writing, Wanda explained that she uses writing to learn as she believes she has to "write things down and see them in print to remember." She further explained how she has notes everywhere and how she often makes and uses lists. She uses writing to help her think, "to make logical sense of something." She explained how she doesn't use writing much to problem solve, as she mostly talks to herself or to someone else. Wanda suggested that talking aloud is a more effective problem solving method for her than writing seems to be. This is one area where individual styles can differ quite dramatically. Some need to put things on paper to effectively problem solve, others, like Wanda, feel they need to talk it out and still others may benefit from a combination of talking and writing. It appears that Wanda may feel she needs to talk it out, yet she needs to then put it on paper to make "sense" of it and to remember, or perhaps she puts it on paper to "help her think" then problem solve further. I wonder if the fact that she has three good women friends with whom she enjoys talking has an effect on her favouring "talking it out" as a means to problem solve, or perhaps her style of talking and sharing has earned her these close friends. Wanda explains that she

uses writing as a means of communication in the way of reports, information and casual correspondence. She uses writing to help her feel, "to relive and sort through." The more I read the transcript on the pre-project interview, the more I saw that Wanda uses writing to problem solve more than she realizes. She says that she doesn't use "writing much to problem solve." Yet, she says that she does use writing to help her "think", to "make logical sense of something" and to "sort through." These are processes that I believe are involved in problem solving. These possibly inconsistent, maybe even contradictory statements, illustrate how interrelated the processes of reading, writing and storytelling are and how complicated the processes of problem solving is in all situations, even more so when they are problematic situations (i.e., mothering a child with special needs). These descriptions of overlapping and interrelated processes are consistent with the impressions and conclusions I made after my literature review.

Wanda described her initial reasons for joining the writing group as a response to a suggestion made by a good friend of hers. She explained that her friend suggested that it "might be interesting to get together and do something different", taking into account that this had to do with mothering a child with special needs. Wanda explained that the types of activities which she enjoys involve doing things that require creativity, like painting, gardening, and working with her hands, even though she suggests that she does not feel she is very good at these activities.

It is interesting to note that Wanda ended her thought on creativity, by adding that she doesn't feel she's very good at writing. She is aware that these are her feelings, which I believe is one step higher on the self-esteem ladder than those women who state firmly "I am not good at it." Yet, she still feels compelled to qualify her statements with

negative self judgments. She continued to discuss why she decided to join the writing group by stating "I also appreciate a good story with well chosen words, colourful language and a glimpse of somebody's unique perspective." Wanda described her expectations of the program as follows: "I am looking forward to spending some time, sharing with a friend and others, in the group on a topic we have in common." She explained that she likes to write and she believed she would like being "forced" into putting her feelings down on paper. The idea of wanting to be forced and to feel pressured to write, was a reason for joining the group, given by many of the participants. This seemed to be a principle similar to joining a group like Weight Watchers to help people lose weight. Wanda said that she was interested in seeing what people have to say. As I read the transcript of this interview, I realized that this phrase was unusual. One usually makes comments such as "read what others wrote", or "hear what the others have to say". "I am interested to see what people have to say" is accurate, yet unusual. She completed her thought by saying "I hope they will be introspective and not blah, blah, mundane!" Wanda's depth of understanding and interpretation, as well as her style of critique is apparent here. She is looking to learn more about issues around people's feelings and human nature. She is not interested in shallow talk. Wanda participated in this group wearing her "mother hat", yet also wore the "para-professional hat" in her part time job as an integration aide. I felt at times, particularly when interviewing Wanda, that she brought different insights and perspectives to her thoughts and words. I also wear many hats, and could thus appreciate her interfering thoughts and roles.

I asked Wanda if she would prefer to read her own written work or have someone else read it. She responded "I am doing this for me. I do not think I care what happens to

my writing, unless I feel that some of the things that come out leave me feeling very exposed and vulnerable." When reading this transcript of the pre-project interview, I found this to be an interesting statement, particularly since during the post-study interview Wanda began by stating that a particularly compelling emotion for her was fear. Wanda seemed to have been frightened by the concern that emotions may be lurking beneath the surface, waiting to be exposed. The idea of vulnerability is one worth considering. Do mothers of children with special needs generally feel more vulnerable? If yes, is this vulnerability felt at all times or only at certain times in their mourning stages and/or in their child's stage of life (i.e., entering school)?

When I asked Wanda about her reading preferences, she responded that she likes reading different things, at different times in her life. At the time of this interview, she was reading to learn, for her work. She had also participated in a mother-daughter book club and she enjoyed reading books for the "pure fun." She commented that she finds Oprah's book suggestions interesting. She ended with "once in a while – especially during the summer, there is nothing like a light, trashy novel." I found it interesting how Wanda prefixed her discussing her "occasional enjoyment of a trashy novel" almost like she was making excuses. "Once in a while-especially during the summer." It is interesting that she commented "especially in the summer." This is probably related to the fact that school is out; it is a time when many parents, especially parents of children with special needs can let their guard down, while they relax and maybe escape even for just a little while. Her need to read trash is consistent with the literature on reading as an escape. I believe this may be related to the fact that she feels she must continually read to learn, to help her son and to help the children and parents she is working with. Is it

possible that helping her son with special needs has even seeped in to her reading pleasure? I asked Wanda to describe her feelings about something she had recently read. She discussed three books in which the author described her experiences as a child and adult with autism. Wanda described these books as recounting the author's "troubled youth, the discovery that she is autistic and the road she takes to pull herself away from the trappings of her autistic world." Wanda described these books as sometimes vague and amazingly well written particularly for a person with autism.

> She exposes all her quirks (a rare opportunity for us neurotypicals to see) and allows the reader to follow her efforts to make sense of society. I take my hat off to her for not only doing what she did but mostly for putting it all into words and exposing herself to the world.

Wanda appreciated Ms. Williams putting it into words, an endorsement I believe, for the value of autobiographies, in helping us to understand the thinking and feeling of others in a way that we can better understand. Wanda uses the phrase "exposing herself" here in an admirable way, whereas she herself was afraid of self-exposure through her own writing. She responded that she liked the style, content and story of Ms Williams' books and that's why she read all three. Wanda stated that she likes to read short stories the most.

When I asked Wanda whether she preferred to write using paper and pen or on computer, she responded that she preferred to use the computer. She explained this choice as follows, "I can write faster and get my thoughts down before they flitter away. I think I prefer writing with pen and paper when I am writing from emotion." It was interesting that Wanda didn't want to be slowed down by writing when her ideas are flowing, yet

when dealing with emotions she likes to use pen and paper. I don't believe she thinks faster than she feels, although this is an interesting notion. The idea of emotions flowing through the pen is a common one, many using expressions like "penning one's anger."

Writing selections.

Since the writing group was based on the participants first and foremost being mothers, I chose to present the following four journal entries written by Wanda. Wanda was very diligent in writing journal entries between workshop sessions and bringing them in. The following are good examples of mothers writing about being mothers.

Journal Entry #1

At the moment I am a proud mother of two teenagers. They are special. The little guys are physical work. You chase them around, pull up their pants, pull them down and pull them up again. Adolescence is all psychological gymnastics. Without even making much of an effort my two teens suck me dry. They burn the fuel that keeps my engine running. And when they see me sitting in a daze, staring blankly ahead, they figure this is a good time to bond and tell me about their life as if I was their closest pal...as if they were actually human.

Journal Entry #2

Motherhood, I highly recommend it. There must be payback sometime. At the moment, I've forgotten what the rewards are now, but I'm working on the future. These kids are going to give me grandchildren I can spoil and ship back at a whim and they are going to take care of me when I get old. And despite the fact that at the moment I just want to get back at them for stealing my 'joie de vivre', I'll probably continue as I have for the last eighteen years, loving them more everyday.

Journal Entry #3

Yes, this is a bad week to regale anyone with the rewards of motherhood. At the moment the endless responsibilities are making me nauseous. Dad of course is the major bread winner and must focus his utmost attention on some stranger's needs first. To be fair, he's always there in a crisis. If only nightly homework, darned projects and getting kids to their weekly extra curricular activities were crises! Each of my children's teachers seems to draw the line back to mom when little Johnny needs attention. My adorable young daughter has a reading problem so her teacher asked for my permission to have her assessed by a speech language pathologist. Hum. Several months after the referral was made I received a call to let me know my little sweetheart has a speech impediment and would like a home program to help "cure her." "Well sure" I said, "in my spare time I would love to order her to run through boring repetitive exercises and while she's at school I could make up fun little games for us to play together!" Get a grip lady! I'm a maid, a nurse, a magician, a chef, an accountant, an administrator and now a speech language pathologist in training. I'll add that to my c.v

Journal Entry #4 "Motherhood"

Whatever possessed me to have unprotected sex with this man! Sure, he's my husband, but what was I thinking, making a baby? Yes, we wanted a family and I couldn't have just one child, we needed to have another and make it a nice round even number. A boy and a girl. So why did I become obsessed with the insane necessity of having just one more? He was so sweet and quiet and cuddly. Worst of all he was needy for no one else but me. Ha, I found out he was a lot more work than I ever bargained for. And still this strong, annoying desire was invading my thoughts again. I just wanted to relive the special moments with a little baby girl; dress her up, dream about her ballet recitals and soccer goals and her spectacular breakthrough into the business world dominated by men.

Wanda uses a style of writing that seemed quite different from that of the other participants. This was particularly evident when she wrote about mothering. Her style appears to be using humour and satire to present some of the issues around mothering. She writes about the demands and the fatigue and the endless responsibilities. She uses phrases such as "they burn the fuel that keeps my engine running" to describe the

common phenomenon of mothers putting their children first and/or of being expected to put their children first. She ends on the positive. "I'll probably continue as I have for the last 18 years, loving them more everyday."

Wanda's writing is highly illustrative of her personality. She appears to be very honest and candid and she tends to use humour as a tool for dealing with the day to day struggles of mothering a child with special needs. At times, she may on the surface be dealing with these issues in a humorous way, yet she is exposing issues which have been, and continue to be, crucial to the mothering literature.

The second passage touches on many of the key issues in the mothering literature. "Dad of course is the major breadwinner and must focus his utmost attention on some stranger's needs first." This is a common issue where the mother is expected to take care of the needs of the household and the children, as the father has "a real job." The breadwinner-homemaker dichotomy is powerful. Wanda softens this with "to be fair he's always there in a crisis" yet, goes on to list all the daily events which certainly should be considered "a crisis" but are not. Two excellent examples of this are homework and extra curricular activities. Wanda also touches on the expectations that teachers, therapists, and other such outsiders, often place on the already overwhelmed mother (i.e., even more exercises, home programs, etc.). Perhaps Wanda was describing mother blaming when she wrote "each of my children's teachers seems to draw the line back to mom when little Johnny needs attention." If not blame, than certainly pointing a finger when it comes to who is going to take care of this. Wanda's humour is certainly effective in portraying the excessive, often overwhelming demands placed on mothers, particularly mothers of

children with special needs. After reading Wanda's passage one must wonder, have we progressed at all, from Bowlby's notion of a 24-7 job for mothers only?

Wanda's third passage, once again satirical, reads as sort of blaming herself for being strapped with the demands of four children. Yet she throws in little phrases such as "he was so sweet and quiet and cuddly" Almost hiding her loving feelings. Wanda ends this passage describing herself as "tired, run down, under-appreciated, stressed and responsible for anything that goes wrong around here." The last few words are totally consistent with the mother guilt/mothers blaming themes. Stress, tired, rundown, and under-appreciated are common themes as well.

Wanda wrote a job description for mothers of children with special needs.

Job Description for Mothers

Neither a mother nor a father is replaceable. Given this fact, the guardian selected to assume this great responsibility must be considered to be the next best thing to a parent. In addition to the needs of growing and developing children, a child with special needs requires a greater commitment on the part of a caregiver. The candidate must have insight into the greater long term possibilities for the child, with the objective of opening as many doors as possible and preparing the child for opportunities. As a parent my goal is to prepare my children to live healthy, independent lives equipped with the ability to make sound, well thought out decisions. This philosophy should be continued and despite the obvious obstacles, continuously nurtured in my child with special needs. Patience, a positive attitude and endurance are an essential element in the success of this goal. It can be achieved by taking the time to listen and engage in frequent conversation with each child in order to understand their point of view and to be able to guide them responsibly.

As well, the caregiver chosen must value education both academic and cultural and instill an appreciation for nature and the preservation of the environment. This would imply the practice of outdoor activities, good nutritional habits and healthy living. The last important quality a caregiver must have is a sense of humor. Laughter will bring you together, and help repair the damages of human nature.

Wanda spoke about the job description writing activity after the program was over. She explained that she had written it in a way of a will (i.e., last will and testament). She felt this helped her formulate her ideas by going through the process of selecting a guardian. She spoke in length about the importance of individual attitudes and temperaments when selecting the person to care for her children. She reported feeling that some good brain storming of ideas came out of this exercise.

A number of the activities during the program were of writing, using a prompt. We had chosen three different types of prompts, one using an object and one using the memory of a significant event, in this case the child with special needs and their first day in kindergarten and the third was using a picture. We had tried writing to two different types of music. For the object as a prompt, Wanda's choice was unusual and very symbolic. She chose a handprint that her son Peter had made for her when he was in preschool. It was interesting to note how this prompt elicited thoughts of Peter's disorder. This was in contrast to Chantal remembering the times when all seemed well while looking at her son's baby bottle. For Wanda, the hand print was screaming "disorder" as the crease in his hand is characteristic of his handicap and the small hands and stubby fingers are reminders of his probable small stature and other problems related to the syndrome that he suffers from. The hand print brought back memories of his diagnosis. Chantal and Wanda both relate their prompt to their child's problems, with Chantal it was when all seems fine, with Wanda it was when it all changed. Wanda began her writing, based on this prompt, as a diary entry.

Wanda's Diary Entry

Dear Diary,

Tucked away in a closet is a box of memorabilia- things only a mother would keep: a lock of baby hair, a home made card, a note from camp, a special craft from school. When I need to be reminded that my children are a true blessing, I pull it out. Today is a Peter day. He is so near to my heart yet the thought of having a break from him for a couple of days appeals to me. When it comes to Peter there is always a flip side to the story. Take this plaster cast of his little hands made in nursery school. His hand looks like all the other little hands in the class. Just one of the kids. But when I look at the imprint a little longer I see the simian crease in his palm that screams out genetic disorder.

All the imprints are small; after all, the children are three and four years old! Peter is five. His imprint is particularly small because he is genetically predisposed to having small hands and stubby fingers. What will it mean for him to be small in stature, a touch uncoordinated and low in stamina? What other surprises are hidden in those hands? Peter made what everybody in the class made, which was a lovely craft, into which he put his heart and soul and gave it to his mom with a loving hug. His hug was particularly special because I knew then that when I hugged him back, we both felt a reciprocal sense of accomplishment and gratitude for our successes and for each other.

In this diary entry, Wanda described many emotions and memories elicited by this prompt. She described ambiguous, conflicting feelings towards her son-"he is so near my heart, yet the thought of having a break from him for a couple of days appeals to me." This is consistent with the literature on mother's ambivalent feelings (Parker, 1997). Wanda's explanation of pulling out memorabilia when she needs to be reminded that her children are a true blessing, described an interesting use of memory prompts (i.e., taking out happy, precious memory prompts when the moments are more difficult). Wanda ends her diary on a positive note, an approach which appears to be common. The reason for this is an area worth investigating; is it a defense, a feeling of guilt for negative thoughts or just the way a mother feels?

Another writing experience using a prompt was to remember the first day of Kindergarten for the child with special needs.

The First Day of School

The milestones that measure a child's developmental progress: sitting up, his first steps, his first words. I didn't realize my son was in a race until we were not getting to the finish line! My child with special needs was a little slow at hitting those milestones...but he did get there with help and determination. We went to the children's Hospital for physio and occupational therapy and then for speech therapy, never all on the same day of course. Services were disjointed and we were lucky to end up at a Center where all these professionals and more worked on a team. My son was making good progress but our time had run out at the Center because he was five and of school age. It was time for the school system to take over. I was mad and I was frustrated! I knew they had little to offer and he still needed so much. I knew that I would have to start paying privately for services the government should be responsible for. And worst of all, I knew I would be losing control. I wouldn't be the puppeteer anymore, I would have to step back and let the school figure out how to best help him with their limited knowledge of this special child and their limited resources. Being an optimist, I crossed my fingers and hoped for the best. We had been to visit the school, I was confident his teachers had a soft spot for him and he was eager to follow in his brother's and sisters' footsteps. He was so excited to take the bus!

He was so cute on the first day of school; all dressed up in navy shorts and a white shirt tucked in neatly, with his new schoolbag hanging from his shoulders. He had to stretch and pull himself up onto the first step of the big orange bus and then all I saw was his little face, smiling at me from the window - the window closest to the bus driver of course! I was free - no kid, somebody else's responsibility! I watched the bus drive down the road and in a panic a voice inside me was screaming: "I put so much time and effort and energy into this little boy, how could I just let him climb into a bus with a stranger at the wheel and send him off to a building full of more strangers!" I got into my car and drove like a crazy woman to the school and waited for him to arrive. He waved at me, and walked straight to his teacher, she took his hand and off they went. Knowing what I know now, I wish they were off riding into the sunset; it would have been such a happy ending. My son was riding into a new adventure called life in the real world and I was facing some new experiences myself.

This particular event was chosen as it is a time where mothers are believed to suffer from many new as well as many recurring emotions. This is a critical time when mothers of children with special needs have been described as experiencing the new stage by returning to old stages of mourning.

What may seem like a simple description of a child's first day of school is a page full of valuable insights into an emotion packed event in the life of both mother and child. The prompt of that day seems to open a dam, allowing a flood of feelings, thoughts, fears, and contradictions to flow onto the paper, allowing the reader a glimpse of what Wanda , as well as other mothers in similar situations, deal with at every fork of her road. She describes how before she even realized it, she was losing in a race she didn't even know that she and Peter had entered. She describes how services were disjointed and then they were not even there at all. Little phrases like "physio and occupational therapy and then for speech therapy, never on the same day of course" are explaining major problems with "the system" where the patient and the family's time are not valued, while the professional's time is considered invaluable. An understanding of something so simple could go miles in healing the parent/professional conflicts and facilitating a path to better health and development. Wanda explained how just when it was coming together, Peter turned five, a not so magic number for children with special needs and their mothers. "I was mad and I was frustrated." These are themes that are recurrent in mothers' repertoires of trying to deal. The ideas of needing to advocate while "losing control" are common to many mothers of school aged children. However, this is particularly apparent when the children do not follow the typical route.

Wanda's ambivalent feelings are illustrated once again in her writing, when she writes about feeling free and then panic. She describes that she had put so much "time and effort and energy into this little boy." She writes about the voice inside her "screaming" and how she "drove like a crazy women." She writes about how she chased after her son in a way that suggested insanity. Is this related to guilt, confusion, embarrassment, and/or cultural values, and expectations? These ambiguities and insecurities are typical and Wanda did an excellent job of portraying them. She ends this passage, sharing her wishes that there could be a happy ending, yet suspicious that it may not be so.

During one of the sessions Wanda and the others wrote two types of music. Wanda completed hers at home and then read them to the group. Her passages are as follows:

Writing to Music (1)

When I sit here and look out the window, I see an amazing lack of life and color. The trees look like tangled wire meshes and the lawn is muddy and patchy. A couple of sparrows pop out of the little birdhouse in our yard. They seem busy preparing a nest I imagine.

I will be busy too today, cleaning my nest! It never ends. I've got the right music to entice me into cleaning with attitude. Rhythm and Blues blasting throughout the house will at least turn my mechanical chores into some kind of cleansing dance. I have until 2:30 to boogie woogie and then the real dance begins.

Hopping from one child to another - checking homework, fetching snacks, shutting the TV again and throwing a little food together for another delectable gourmet meal. Like the beat of a drum, I keep going until I crash. Another day done. Will they ever leave home?

Writing To Music (2)

Once I walked into a quaint little shop in a small rustic town. The music playing was light and airy and made me think of a secret place in the woods where fairies jump around and play in the greenery. The store was full of imaginative pieces of sparkling glass, fanciful jewelry, pictures of daydreams and the smell of incense.

I wished I could close my eyes and be in another place; like being on a cloud where I feel real but there is no reality. Where every child is happy and playing without a care- free of the human frailties that force them to struggle. Free of the traps that control their destiny. Children should be making noise, yelling and running and laughing out loud. It's so much fun to watch them just being themselves, because it's good, because we need to keep some of that playfulness when we are adults. It keeps us balanced.

I can imagine my child with special needs, happy- running and playing with others- no different. That's an imaginary place I like.

In the first passage, Wanda portrays the challenges of motherhood using some humour. The fast beat of the music that Wanda chose as a prompt seems to inspire her to move around while she finishes mundane work. She uses imagery to portray the fast moves required to get through her busy days.

The light, airy music in the second passage helped take Wanda away to a special, safe place, where children are carefree and happy, where her child with special needs is carefree and happy and "like everyone else." This passage, particularly the last part, is a common dream shared by mothers of children with special needs (i.e., that their children be happy, carefree and most important "typical").

Wanda identified the piece of writing that affected her in a significant way as the angry letter that she had written. She wrote about that letter as follows, "I liked the letter that I will never send to the awful person who entered our life and upset us all." She

continued writing that this woman was only one of many. She described the letter that she had written for that particular writing activity (i.e., an angry letter), as a text that was "bitter and angry." She felt that writing the letter "perhaps helped her lay some of this anger to rest." This reaction after writing an angry letter was common (i.e., perhaps laying it to rest). Wanda, in her letter, addressed this specifically to one individual and clearly chose to include her name as Wanda's anger was still so deep and so directed. I omitted the name in this text to protect Wanda's and the other women's confidentiality.

Wanda's Angry Letter

Three years have passed and when I look back at the time you spent with my son, a rage builds up inside of me. I want to hit you and shake you and give back some of the violence you awoke in my son. Anger and hurt and a strong need to make you understand that your intolerance towards a child with needs, different from the ones you know, hurt us both irreparably.

I do not believe you were evil or calculatingly mean, plotting to make life miserable for my son. I think you just did not care enough to make an effort. Your lack of empathy was destructive. When Peter had fit after tantrum in class, it was surely because he was a manipulative, lazy and spoiled child. It was a negative, adversarial relationship that evolved over time between the two of you and in retrospect I see how that influence ate away at Peter's resilience. When he needed time and space you challenged him, when he needed encouragement and coaxing, you threatened him and when patience was essential you pressured him. I saw it, I heard about it from other parent witnesses and from teachers who felt the need to alert me. I saw you throw him into the principal's office for disciplining and I remember the dispassionate look in your face. Teachers heard him crying and one mother was appalled because you brought him outside in the bitter cold with no coat on because he refused to get dressed.

You were a bad match for Peter and he for you. I went to the teacher and I went to the principal. I asked for changes and then I begged. Again and again I was told to be patient and to give you a chance. I regret I never faced you eye to eye. Perhaps I was a coward or perhaps I just instinctively knew I would feel only more frustration. How could you spend day after day with a child who was repeatedly disruptive in class, whose tantrums were increasingly louder, more

frequent and more violent. Each day he seemed to rebel at every task thrown his way. How could you be part of an ugly situation and not try to desperately improve things. I wonder if you ever accepted any responsibility for the difficulties that were so evident. Was there an effort to try and understand him, to ask about his challenges and his weaknesses? I never caught a glimpse of caring that would have helped you see a child with aspirations to succeed and to fit in, to be able to work as well and as fast as the others, to be smart and flexible and sociable. Did you know he thought of himself as capable until his inabilities were underlined to the point of killing his desire to even try.

When you were hired to guide and help my son, I learned that not all people who work with children are meant to be there and that the needs of a child do not always come first. I lost my innocent view of a tolerant world of opportunities and gained a skepticism fuelled by fury. We have worked hard to break away from the unacceptable behavior patterns learned that year. It has not been easy and they surface to haunt us regularly.

I have promised myself that I will be a better advocate for my son in the future. I will not let him down again. As you continue to work with children, I hope this letter will help you remember how influential you can be in a child's life as well as in a mother's!

Although this letter starts out very angry, even aggressive, the tone quickly calms. It shows hints of advocacy and of an effort to awaken and teach this apparently ineffective educator. It is important to note the degree of rage erupting even many years after the time this educator was with Peter. Wanda writes about anger, hurt, and a strong need to make her understand. These are all common emotions felt by mothers of children with special needs. Her hurt and anger may or may not be understood by others however, this need to make others understand is one that is rarely, if not ever, understood by those who have not worn the shoes of a mother whose child has special needs. Wanda's frustration, her rage, and her disappointment are most apparent in her writing. Her putting her anger to rest also seeps through as her words become more calm and mild towards the

end of the letter. Wanda's guilt and sense of responsibility seeps through as well when she writes how she regrets that she never met the educator "face to face." She chastised herself with comments such as "perhaps I was a coward or perhaps I knew I would only feel more frustration" and "I promised myself that I will be a better advocate for my son in the future. I will not let him down again." What a big responsibility and what a horrible feeling to know that she tried and tried, but to feel that she had let her son down. These feelings of a need to fight, to advocate and to never let the child down is seen as paramount in the writings and in the lives of mothers who have children with special needs.

Anecdotal comments.

During a discussion on writing stories and letters to "advice givers" (i.e., people who feel the need to ask hurtful questions and/or give unsolicited advice), Wanda commented on what she referred to as a "gap from mouth to paper." She also commented on the fact that when we read things, we put our "own slant on it." This is consistent with the research suggesting that the reader's life experience interacts with the written material to form the reader's understanding and perception of the materials. Wanda suggested that "with writing we only have words." I believe she was referring to the lack of non-verbal cues (i.e., body posture, facial expression, tone of voice, intensity of voice, etc.). Her thoughts on this may be related to her paraprofessional work and/or to her efforts at helping her son Peter improve his verbal and non-verbal communication. It is interesting to note that Peter seems to take comfort in the written word. She expressed her desire to read her written work to a friend.

Post-project interview.

After Sally's suggestion of writing responses to interview questions, Wanda began by writing her responses and then we met to discuss these responses. Wanda, like many of the other participants, described how she liked to have specific writing activities as "it makes you do it." Wanda described her feelings after writing an angry letter. It appears that Wanda was inspired by her angry letter to an educator, as she made the following very specific comments: "battle of the judges- looking at all the pieces … so many courts along the way", "the professionals are not on the battleground." As I re-read my notes on the post-project interview, they served as prompts for many of my own memories. I am reminded, for example, of the recurring fictional nightmare described by Pearson (2002) when she describes the main character, a working mother's recurrent nightmare of being called to the "court of mothering" for being a "bad mother."

Wanda wrote that she had initially joined the writing group to see the effect that writing would have on her perspective as a parent of a child with special needs. "What did I really think?" She wrote that she wanted to see if others thought the same way that she did. This truly highlights the benefits of reading the reflections and experiences of another individual. The benefits appear evident, even if the reading and writing are solitary experiences and even more so, if they are a part of a group experience.

Wanda wrote that she didn't have any preconceived objectives for the writing program other than to try guided writing and to do it because of a deadline. She had looked forward to hearing what others had written mostly "how my friend in the group

had penned her thoughts." Many of the women I interviewed spoke or wrote about and explained how they wanted and needed deadlines to produce writing.

In response to the question of whether she felt she had accomplished any of her goals, Wanda wrote that she was happy to have the chance to write because "being forced to do it was the only way it was going to get done." I wonder if this need for deadlines and pressures is so prevalent for mothers of children with special needs, as they feel so many pulling responsibilities and that only if and when writing becomes a responsibility with a time limit, will it receive the priority they wanted it to have. The benefits that Wanda received, that she hadn't planned on or expected were that she found "it was interesting to see where my ideas took me in exploring feelings and putting them into words. I was glad to have the chance to put some time aside for myself." The theme of "time for myself" was a common one. This is an experience that many mothers hesitated to "allow" themselves. Wanda most enjoyed when someone came up with a good text or even a point of a text that she thought was "neat." She least enjoyed when the group got off topic or away from what "we were there for." She did not like when members of the group did not show up because then "the pool of writing became too small."

In preparing for the post-project interview Wanda had gone through her papers and found some old newsletters. Wanda explained how she felt pleased to realize that she had written and edited many newsletters, at various levels of her children's education. She had apparently forgotten about these writing accomplishments until she was preparing her answers for the interview questions after this project had been completed. She found a file containing these newsletters and proudly brought them in to share with me. She smiled as she looked at them again and saw her thoughts and ideas in print. It is

interesting that she had not recalled these newsletters at the initial interview. It's as if the writing experiences, during the project, served as a prompt to remember earlier, positive writing experiences. This was similar to Chantal remembering that she used to write poetry.

In responding to the question of whether she felt affected by the writing of the other participants, she wrote that the texts that her friend wrote and brought in were "amazing." She wrote "I did not know she was so smart" (i.e., description of the participant that brought her to the writing program). It's interesting that many people equate good writing with being smart.

For the question on the impact of the oral discussions of the writing, Wanda had not responded in writing, yet she offered some good insight when we spoke about this in our interview. I wondered if it was a coincidence that Wanda was more productive orally when analyzing the discussion parts and wrote more about the writing parts of the program. Wanda explained that she did not feel that there had been any significant impact from discussions, yet she found some of the discussions interesting. She enjoyed the discussions about Chantal's poem the *Dragon Slayers*. She talked about the meaning that the Dragon elicits, such evil, saviour, dream like, taking dreams and putting them into the action and not realistic. Wanda discussed the notion and visualization of "going into his head slaying dragons."

She described her overall feeling of the experience of the program to be "interesting." She wrote, as she did throughout the questionnaire, that she would have liked a group that was bigger; she suggested twice the size. She would have liked to "get more samples and more variety, one topic-different takes."

Wanda wrote that she hadn't really changed in any way after the program. During our discussion, she explained that she believes that "at the time, your thinking changes you because you explore." With regards to suggestions and recommendations for a writing workshop in the future, Wanda focused on the size of the group. She suggested that if the group has too many participants, you don't get to share, but she suggested that you need enough participants to get enough "samples." She wanted to have people write on the same topic, how they deal with it, etc. Wanda's frequent use of group size and sample makes me wonder if her educational background and her work in the field played a role in her orientation and her needs. Wanda spoke about her friend Sheila and her writing. She explained how she likes the style Sheila used to introduce herself - using chapters to describe the stages of her life (for example, Chapter One – her own childhood). This method of introduction was different than what most of the other participants had used, both in its organization and in that it started much before Sheila became a mother. Wanda also enjoyed how Sheila tried to put herself into her son's head. She explains how she felt getting into someone else's head and thoughts may be a good thing to try and do yet, she expressed her concern that this type of exercise might be difficult as "you can lose yourself." She suggested however that "when you write you can come back and re-read it and see if that's what you really think is happening." This is consistent with suggestions from researchers such as Van Manen (1990).

One of the reasons that Wanda gives for her joining the group was to be with and learn more about her friend Sheila. After listening to Sheila's poem about her son Keith, Wanda commented that Sheila's words reminded her of a scene. I believe the poem served as a prompt to a shared memory. Wanda continued by saying to Sheila "words, not

phrases....that's Keith." I've presented Sheila's poem here to illustrates the text that Wanda was referring to and discussing.

Sheila's Poem

To be inside his head
To perceive as he does,
A bombardment of sounds and images
To pick out the ones needed at any given moment
To be able to function on task as those around him.
What must it feel like to be him?
Waking up with uncontrollable energy to expend
Within the confines of a still-sleeping family and walls that restrain
To seek comfort in physical contact, although inappropriate
Or to bounce on the sofa while listening to music other might not define as soothing.
As the ability to control oneself becomes more and more difficult,
And if flight were within my capabilities,
I'd have embarked on a long journey by now
Or have mowed several lawns or shoveled various driveways
It becomes time for medication to relax my motion and calm my mind.
Life becomes manageable, although perception is muted
The insight into life I experience when I am me
Becomes veiled by an imposed serenity I otherwise am not capable of
To reach a balance is the goal.
I possess strength of spirit I require
In order to continually compensate for those things those are difficult
This becomes my realm of giftedness
I demonstrate great perseverance as a trumpet in a string quartet
People are drawn to that fortitude and unrelentless drive to move forward
Constantly swimming upstream
(the transformation from the third to writing in the first person, was a natural one- trying to really feel like him)

This changing of voices from that of the mother's to that of her child, was similar to the approach Chantal used in the *Dragon Slayers*. It may be an attempt to understand the child, to speak for the child and/or as a sense of comfort (i.e., "mom, don't worry I'm o.k."). It may at some level be an attempt at illustrating the close mother-child bond. A

theme often discussed by the mothers was that of advocating - speaking for their children, being their voice. This appeared indirectly in some of their writing as well.

After Wanda and I discussed her responses to the open ended questions on the post workshop questionnaire, we continued talking. Wanda began talking about writing, she described how putting it on paper helps organize, underline and explain. "See how it's not fleeting, it's there, it's more permanent when it's written." She suggested using the computer, which facilitates this. She described how once you write it down, it's the real thing, factual, like you've accepted it. She explains this doesn't mean you can't change it, like the period at the end of something, but it is a means of saving it. Wanda believes it is easier to be more methodical in writing as you are trying to go step by step. She suggested that even when brainstorming, it's more logical when written down. She described herself as "the king of organizing the order of things, etc.," particularly when she was in university.

I showed Wanda the list of themes that I had developed on the basis of the writings of all the participants and I waited to hear her impressions. Wanda commented on how the many negative themes that she saw on the list made her feel sad. This was a fairly common reaction.

She described how people "taint everything" she believes. Only then, when we get some distance, can we begin to see the positives. She described some of what she considered the positives outcomes of this situation (i.e., mothering a child with special needs). For example meeting special people, "interesting, caring people." She described how for her, "life took another direction." This reminded me of the well known narrative

"Welcome to Holland," which is written by a mother of a child with Down syndrome (see Appendix B).

Wanda then began talking about writing and how it can be considered an art. She described how the artist is in a "manic state...intensity in brain waves." When the person is intensely happy they can be "physically expressive." I then showed Wanda the list of themes at the end of this chapter, as well as the chapter headings (See Appendix G) as she had not participated in that process. I was interested in her reaction to this. She responded with sadness, she explained her sadness as a reaction to the overwhelmingly large number of negative emotions. She began to talk about chapter headings in general. She described how she had recently picked up a book and felt it was not clear from the titles, what was in the chapter.

Wanda commented specifically on the chapter heading titled "my child is a person not a diagnosis." Wanda felt that we can't do anything until we take this out of the doctor's hand. She explained how she feels this shouldn't be under a medical model. We talked about how some collections of mother's stories have emerged over the last couple of years and that the need for our collection to be printed may have decreased since we initially conceived of the idea. Wanda responded that each collection is different, with new dimensions to offer.

Wanda commented that at times when she's reading, her reaction will be "so smart." She doesn't always see it when people are talking, Wanda explained that to her hearing someone speak is often just "blah blah" but on paper it's so organized. She likes to read, but sometimes gets the feeling "how come I can't write that." Wanda enjoys reading most when people use "colourful language and create a feeling or an image."

Wanda frequently spoke or wrote about her friend Sheila, asking her to join the group and to not "be idle." She explained how she didn't care what happened to her writing. She was surprised and pleased with some of the writing she produced, particularly "the spontaneous stuff." She commented on how she could "fix it up" when discussing her writing. When discussing the writings of others, she contrasted those who were "not good at putting words on paper" with others who used "terrific imagery." Again, Wanda differed from the others in this area, where she was more judgmental and/or more communicative about her judgments of the participation of others and the quality of their work. I can only speculate upon whether this is related to her particular personality make up, to her paraprofessional orientation or to a combination of these two factors.

I end this section with two narratives that Wanda brought to me after the program was completed. Both narratives show much insight and thought, a number of references to the importance placed on books, the conflicts between parents and teachers and the important roles that both parents and teachers must play. It was exciting to see that Wanda was continuing to write after the program, in a way she never had before.

Narrative #1

I wonder about a lot of things- wondering seems to be the way I process information. Being the parent of four children gives me the opportunity to wonder about a lot of things. Having a child with special needs gives me a whole new and interesting selection of things I wonder about.

Lately, I've been thinking about how totally wrong some professionals can be...and you'd think they should know better. I, on the other hand, can substantiate my point of view by saying my ideas come from my gut and my cumulative experiences as a mother. I never studied to get here; I've just lived this knowledge.

My son's teacher, backed by a consultant and the principal, thinks my son should learn to work in class independently and be weaned off his teacher's aid. Noble goal, I agree. The process has not been smooth. In a bad moment, he tantrums, refuses to cooperate and puts the work aside. They try to convince him and strategize but I can't see they are getting anywhere. In a moment of wondering, I drew a parallel with the situation of a young baby. Under the age of one, children have very specific needs. They are evident and basic. They cry to communicate that their needs must be met, and not to manipulate as some people think. You could never think a tiny baby is manipulative! If a mother meets these needs and provides a secure and comforting environment for her child, he will grow with a sense of confidence. This confidence will lead the child to want to explore on his own and become more and more independent. I'm sure I've read this in a book somewhere. I know I have lived it with my own children. When they are ready, they let me know. Their agenda, their own timing, not mine. Seem to work best.

So why....explain to me why....teachers feel the need to force my son to give up a support which seems to meet his needs and allow him to function with confidence. I get their point, but there has to be a better way of going about the task. You want him to be independent, ask him what he's ready for and encourage him. Don't decide it's time to take away his "shadow" because it's on your agenda. Do these professionals follow a book that says: "...and now we must do this!" (Whether the child is ready or not!)

I realize there are different factors that come into play in his situation, but it just struck me that we must adapt to suit the learner and try to avoid the "one way of doing things" approach.

Narrative #2

The jury is still out...is she a terrific teacher who struggles day in and day out with my difficult son...or...is she one of those teachers who constantly makes you want to pull your hair out? Oh, to be a fly on the wall in that class! I'll bet my recurring dream of becoming a little black bug with wings is common to many parents, especially those of a special needs child! How does this teacher talk to him? Does she see his bright potential and all the strengths that make him a unique learner and interesting individual? Does she rise to the challenge of motivating him when conventional approaches don't seem to work? Does she see how far he's come and how much it took to get there? Oh my God! Does she talk down to him because his intellect is obviously inferior to another child of the same age!? Does she feel sorry for him, does she allow him latitude because after all, he won't be going too far in life anyways. Are my son's temper tantrums a

result of her pushing his buttons, of a discipline method that frustrates him? Are they the result of a child who can't find the words and doesn't have the tools to cope with "life"?

I can't figure it out.

The teachers appear so competent during our interviews. She seems respectful, attentive to detail and sensitive to his struggles. But when she talks the talk is it really what she does in the classroom? The best I could do is to find myself a spy, volunteer to help out and observe and of course, do what I've always done for my son....find the best way to help him cope.

But I'd still like to be a fly on the wall.

It is interesting to see that the themes don't change: advocacy, worry, needing to trust, and parent-teacher conflicts are common in these narratives and Wanda has turned to the writing process and to the written word to help her deal with these recurring feelings and issues.

Belinda's Story

Our work was not yet done. Baby two was to come. But before he came I had a moment to love my daughter. My sweet little girl who hardly moved or kicked inside me and now lay on my belly and I knew. I knew there was something not right. I looked in her eyes and I loved her immediately as I reluctantly gave her to the doctor, to deliver the twin.

I started this story with a portion of Belinda's writing using the birth of her twins as a memory prompt. Her loving thoughts towards her baby girl are apparent. This quote

also illustrates the power of maternal instinct. A mother's feeling that something is wrong is consistent with the autobiographical literature, but not with the professional literature.

Belinda is a pleasant, attractive, energetic woman in her 40's, who is married to a lawyer. She is the mother of three children and a stepdaughter. Her older son was developing without incidence, life was moving along and then she became pregnant and gave birth to twins, a boy and a girl. Her daughter, Cathy, very quickly presented with developmental delays. Belinda quickly responded by becoming involved with her, taking her to therapies, doctors and special schools. Little by little, the "healthy twin", Charlie was exhibiting behavioural problems; unknown to anyone that he too had problems. Charlie was at least average intelligence, perhaps more. However, he was suffering from ADHD and some possible learning difficulties. So Belinda set off to deal with both twins' problems, while caring for her older son, her stepdaughter, her husband, her mother, her dog, her many good friends and oh, yes, herself, with her own medical problems and a growing awareness that she too may have always had attention and learning difficulties. On the outside, we see a beautiful, put together, well dressed and well liked, popular woman. Inside, she is riddled with inconsistencies, insecurities, and unfulfilled dreams. Always smiling and appearing grateful, Belinda explains that she loves to join support groups to share and learn from others. After the writing program, Belinda had begun to develop a career working in a Social Service Agency.

Belinda had participated in the same mothering discussion group as Sally. She chose to participate in the writing group. However, she was very concerned about the writing aspect. She wanted the sharing and the support components, but was very concerned about her ability or in her own words, "inability to write."

Pre-project interview.

Belinda was happy to participate in the preliminary interview as it was a talking session and she happily reported that she loves to talk. Belinda's earliest memories of writing she "guesses" were in grade school. She explained that in her adult life, her writing consists of list making. "I don't write, I make lists." She had used writing at different times in her life to learn (i.e., by making notes). She feels she uses writing to help her remember, but not to help her think. She uses writing to problem solve by "the pros and cons kind of thing." She uses writing to communicate by writing letters and leaving notes. She uses writing to help her feel, or to deal with her feelings, by keeping a journal from time to time. She explained that she joined the writing group as she wanted "the introspection" and she is "always interested in something new."

When I asked her about her expectations, objectives, hopes and fears, she spoke first about her fears. "My fear is that I will not be able to write anything and showing a side of me that I haven't shown to you and to the group, that I won't be smart enough, that is always my fear in life." Belinda, like Wanda and many of the others, equates writing ability with intelligence. Belinda feared that her writing was not good enough and that she may expose herself as not being smart enough. Her worry of being "exposed" was similar to Wanda's. However, Wanda appeared more concerned about emotional exposure, whereas Belinda seemed more concerned about intellectual exposure. Regardless of the nature of the exposure, it appears that a common belief and/or fear is that one's writing may become a window into one's mind, be it thinking or feeling or both. Belinda then discussed her hopes and objectives for herself in the writing group. She responded:

> I'm looking for I think ways of better understanding myself; maybe learn strategies to learn to cope with my life. I think if I can find ways to calm myself down, I will be better able to deal with everything, so if writing helps me, basically get my head in a good place, which is my ultimate goal in life.

It sounds like Belinda was hoping to think, problem solve and deal with her feelings through her writing. She also hoped to use writing to calm herself down, most probably when she felt angry, and/or frustrated, however, maybe when she felt excitement and/or other emotions as well.

Belinda's focus was having a place to share her feelings with others, to vent and hopefully problem solve. Belinda was looking to a group for the experience of sharing and support. Belinda may have been worried about her writing ability or as she believed lack of it, while she feared how she and her work would be perceived by others. However, she was equally, if not more hopeful that her efforts at writing would produce positive cognitive and therapeutic outcomes.

Belinda and I spoke about her reading preferences. She spoke of novels, particularly suspense novels. She said that she likes John Grisham as an author and she likes to read magazines particularly *People* and that sort of magazine. She also said she likes what she referred to as "self-help" books; although she explained that she never finishes the self help books. "You read parts of it or you stop halfway." She reported that she did finish one book, she didn't say which. She said that sometimes she looks in the index. What she had enjoyed reading in the time just prior to the interview was *The Testament* by John Grisham. She enjoyed it, but she didn't feel it had much of an impact

on her. She didn't feel that she could describe the style of the book, as she didn't feel she had knowledge of style. She added "so that is where I feel stupid when it comes to these things." This comment once again suggested that she feels her insecurities around reading and writing. I encouraged Belinda to discuss style not necessarily from a technical point of view, but from an enjoyment point of view. She described how the book *The Testament* immediately captured her attention. She was excited in her description which was as follows:

> Definitely it swallowed me up right away. It got me right into the story. It did not take me 100 pages to feel like I was in it. It was immediate, I was there, I was part of the book, and I was part of the story. I felt intrigued to go on. The content was great. It touched on many people's lives. Different family members, it was about a law firm. I am often interested in television shows, and books that have to do with the legal happening. The legal process I found intriguing-the lawyers had just been through a lot of things that were interesting, then they ended up in the jungle, there were many different aspects. The people were not, well maybe they were everyday. You know what it was, this guy you were, one of the main characters, you were on his journey. His journey through a recovery period, through a growth period and it was very interesting. That was what was interesting to me. You were kind of following his journey and it was an interesting journey. And the impact on you. I came away from the book with a feeling that we, you know when your life gets so difficult and so complex and whatever and you have to go after the simple things and

> make peace with certain things, that is what I got out of this book. I remember calling Stanley (her husband), and I said you know you have to let go of certain things and make peace with God, peace with something. I loved the book.

Belinda's words are wonderful at presenting how one can get lost in a book, become the character, travel their journeys and return with new insights and feelings, new ideas on life, rejuvenated, with a resolve to conquer and accomplish. In two short paragraphs, Belinda described the uses and processes of reading and bibliotherapy described by published authors on the topic (Gold, 1990). She may not feel able to discuss style of writing, but she was eloquent in describing the uses of reading as a therapy.

I asked Belinda about the aspect of style and content that she feels is important in her critique of the writing of others. She told a story of how her aunt had just sent her a book that she had written. Her aunt had sent this book to five or six people before she went the "next step." Her aunt wanted to see what the five or six readers felt about her book. She then posed what I believed was a rhetorical question "Where do I come to be a literary?", explaining that she is not an expert in the field of literature. I asked her when she would read her aunt's book what would she look for. She responded:

> The first things I look for is how long does it take me to get into this book. I think that is the first thing. Especially me who can get bored and has trouble paying attention to it. I do not want to read 100 pages before I'm liking the book. I want to be in there.

She explained that what she liked about her aunt's book was that she didn't have to try to continue reading it. She found that it was interesting, it had characters. "So you immediately wanted to find out more about the characters. So that interested me." She discussed whether everybody wants to read high interest writing. She believes that yet, she then added maybe not everyone feels that way and explained "there are times when I want to sit down and read something more serious and more factual and sometimes when I want more entertainment." Again Belinda was successful at discussing reading, different types and the values, etc. Yet, she did manage to point out what she felt were her weaknesses (i.e., trouble paying attention). As a side note, my initial goal with this project was to help mothers deal with their children's special needs. However, through their writings, I was forced to consider the mothers' profiles and needs as well. I believe this to be a critical aspect when working with children with special needs and their families whether in a research, education or clinical domain. We must consider that the mother also has a profile of strength and weaknesses and her own set of needs.

Belinda preferred to write using pencil and paper because she described herself as "computer illiterate." When I asked Belinda what she would like to work on with respect to writing, she responded "I would like to get into writing a journal on a regular basis, I think that would be good for me. If I had an autobiography that would be a really interesting thing. I have led a very interesting life."

For many of the reasons listed above, Belinda handed in very few written pieces. This was related mostly to her insecurities about her writing abilities and the fact that her thoughts were much faster than her hand and pen. She did continue to be interested in the writing and thoughts of others and in expressing verbally her own thoughts and ideas. Her

attendance was good, particularly in the beginning and middle sessions. She did gradually become frustrated by the quantity or what she believed to be a lack of quantity of her writing contributions. I have only a few written pieces from Belinda. However, my notes on her anecdotal comments are extensive, and my transcripts on her pre and post interviews are rich. I therefore included her as one of the participants in this stories section. As well, I feel it is important to discuss the negative aspects of a writing program for some mothers and to look at those perspectives, which may in some ways differ from the perspectives of the other participants. What's very interesting is how often her perceptions did not differ from those of the other participants, but were rather very consistent, a strong illustration of the many common themes and emotions felt by mothers of children with special needs. Of the few written pieces that Belinda submitted, one was a memoir of a time that was very important in her life. The delivery of her twins was a prompt which elicited many fond memories. This was a prompt that quickly worked at retrieving her memories. Belinda completed the writing activity quickly and was excited to hand it in.

Belinda's Memoir

July 27, 1988, 6 a.m. finally came and Stanley and I were certainly ready. We were being induced because these babies just weren't budging. At 38 ½ weeks, the doctor said it was time. I really felt like a star. My name was on the board in the case room. A team was ready for me, "the twin delivery." Boy was this exciting! Even the room we got was deluxe. Stanley had an extra bed to lie down in and read the paper while they got me ready.

Ready, did they ever get me ready? Monitors everywhere. And people. I had more nurses on me. I couldn't believe it. But I have to say, all the while, I did feel pretty great and certainly knew these babies of ours were in good hands.

I was hooked up to the inducer fluid pertussin at 8:00 a.m. and then the epidural because baby #2 was breached. They had to be prepared for an emergency C-section. Well, everything went well. The doctor checked me at 12:00 and said it would be a while yet but at 1:15 p.m. or so I know that I was ready. I forgot to mention that just before this they lost the heartbeat of baby #2, the breached baby on the monitor. Of course Stanley and I freaked. What happened was as baby #1 went lower into the canal, #2 flipped into place. So with everyone in place, where was the doctor? By 1:30 I was really ready. It was July, all the new residents were in, everyone had tried to get at the twin mom's cervix with no luck and I was going into labor. They prepped me on the table, legs up in the air, socks on and my men were ready, Stanley by my side and the doctor appears as promised from who knows where. My water still had not broken. Can you imagine that? Fully dilated, 11 pounds of baby pushing to get out and not broken yet. Well the doctor took care of that. He broke my water and with what seemed like seconds, baby #1 came out. A baby girl, Stanley cut the cord; they wrapped her, and put her on my stomach. As with my first delivery, I cried when I first saw my baby and the room was finally quiet for a minute. The 30 or so residents behind that congregated at the door, the nurses and the doctor. The residents in rooms tried to give Stanley and I a moment to bond with our daughter before the action started up again. Our work was not yet done. Baby #2 was to come. But before he came I had a moment to love my daughter. My sweet little girl who hardly moved or kicked inside me and now lay on my belly and I knew. I knew there was something not just right. I looked in her eyes and I loved her immediately as I reluctantly gave her to the doctor to deliver her twin.

This baby wasn't coming as easily. The cord decided to come first. The nurse leaned on my belly, the doctor shipped an extra snip, and as his elbow disappeared a minute later after a few good pushes, out came #2. My rambunctious baby #2. No surprise, a little boy. This was baby #2 who never stopped moving and hasn't stopped since. Well, we were pretty proud that day. Everything seemed very normal. Nothing was blatant. Charlie ,#2, was 5lb 7oz. Cathie 5lb 3oz.

Stanley and I were thrilled.

Anecdotal comments.

Belinda commented, during a general discussion on writing, that she realized it's difficult "delving into me." She expressed how she found it harder to write than to speak. She expressed how she had no feelings while writing. The general consensus, with Belinda as part of the discussion, was that with writing they went deeper, clearer and more descriptive. There was more in one shot, not bits and drabs. These comments were inconsistent with Belinda's style and her perceived abilities, which may have added to her discomfort. The group also discussed "respect for the written word", which is in line with Belinda's and Wanda's equating writing ability with intelligence.

After Chantal's first presentation of the *Dragon Slayers*, Belinda commented on how she admired Chantal's "courage to go there." She discussed Chantal's choice of words "hunt down" and "slay." She liked the thought of dragons and the way Chantal's poem "opens, then soothes."

Belinda described how when she was writing, she was thinking this is going to work for herself, not for Harriet. I was very pleased when I read my field notes to find this comment, as I worried when I read that Sally joined the group at first not to let Harriet down. It was concerning however that she had to think about the fact that she wasn't doing it for me, as I questioned whether this was for her an issue. I find it interesting that Sally felt she participated at least in the beginning not to let me down and Belinda did it for herself. Yet in their memory work, Sally describes the benefits to herself in great detail, Belinda remembered few positive details.

During one session, Belinda made a comment which at first I thought was contrary to everything she had said in the pre and post interviews. She proclaimed "once I

started writing, I could have written a book." When I reflected on this comment, I realized it wasn't in fact contrary. Belinda had described her difficulty in writing to be related to being disorganized and to not knowing where to begin. Yet, once she got herself started, she could go on and on. This description of her writing is indicative of her attention difficulties and could be diagnostic in nature. Perhaps if she could work through her writing, she could be more organized in her life, a need that she has often expressed.

Belinda at one point said to the group "writing... the best, especially writing anger." She completed her thought by saying "then sharing is releasing and cleansing." Even though she describes the therapeutic advantages of "sharing", she certainly remembers only the speaking/talking parts, not the writing parts of the program. This may be that the painful parts of writing and/or her insecurities about her writing make it more difficult to remember than the pleasant aspects of verbal discussion, an area where she feels she excels.

During one session, when Belinda read what she had written in a journal entry, her combination of reading and storytelling was very interesting. She then commented on the process. She described how she hesitated when she read her own errors, trying to self-correct while reading. She commented that the content was great and there was humour. She felt that "the words lost things" and she had to stop to elaborate. She felt there was some good problem solving. However, she commented about the passage as follows: "I didn't go into great detail. I didn't put everything down that was in my head." She elaborated a lot on the experience while reading and at one point in her reading, she lost her place in the text after a lengthy verbal discussion. This illustrated to me that Belinda does at some level benefit from writing, if only as a springboard to storytelling. What

became more and more clear are Belinda's insecurities about her writing, or in this case it may have been oral reading (i.e., her hesitations when she reads with errors and her comments that she didn't put everything down). The other illustration is of her love for storytelling and the benefits she receives from the act of oral storytelling.

At a later session, Belinda seemed to be expressing more rather than less difficulty writing. She described having trouble getting anything on paper, difficulties sitting down and "doing it." She described herself as having a "processing problem." During this time, Belinda had been learning more about her son Charlie's Attention Deficit Disorder and was questioning her own learning profile. It's difficult to ascertain whether this accentuated her writing difficulties, whether her writing difficulties pushed her harder to question whether she herself suffered from an attention difficulty or some combination. However, this is another example of how the mourning stage that a person is at during a certain time, may impact their thinking, perceptions and feelings. This was a time where she had begun a new mourning process for her son Charlie, as he was finally being diagnosed. What was important was that the writing at this point was more of a thorn than a therapy for Belinda. Belinda also commented on the insecurity of the writing being in "black and white." Again, this could be because of writing weaknesses or because of the potential exposure of her feelings.

When discussing the mother job description, Belinda commented that at the end she realized there was no feeling. She felt this minimizes what she does. She commented that she judges herself and her level of satisfaction by her children's day. This is consistent with the literature suggesting mothers are judged and/or judge themselves by their children's behaviours, successes, and failures. Belinda described her "need for

approval." She commented "I am always wondering if I am doing my best." The comments concluded with Wanda suggesting to Belinda "write it down then you can think it out." It appeared that Wanda believed that writing could help, rather than frustrate Belinda.

As I went through all my notes, I found as I had suspected, that although Belinda handed in few written pieces, she was a valuable contributor to the group, particularly in her many verbal comments. These comments were often triggered by her own writing experiences, positive and negative and by the written works of others.

Post-project interview.

At the post-project interview, Belinda recalled the writing group as a mother's group that evolved into a writing group. It sounded like she recalled it as just happening, rather than feeling that she had chosen to join this group. When I asked her if she felt she had accomplished any of her initial objectives, she responded that "if anything, it made me feel even more unorganized and confirmed my lack of organization, inability to function in a regular way." Belinda was overtly upset, near tears, when responding to this question. Yet, the pieces of the writing she did submit were rather organized and she had been a contributing member of the group. She later commented on her poor memory and on recent revelations about her own attention and learning issues. This is important in our understanding of memory work and how our perceptions and life situations have an impact on our memories.

I began to wonder how often when studying memory work and false memories, we look at the memory functioning of the individual, and as I have previously discussed, does this matter or is it the perception of the memories that is more important?

Belinda expressed concern that her responses may not be helpful to my research as she felt negative towards writing. I assured her that the contrary was true. That her feelings, thoughts, memories and perceptions were of great importance to my understanding of writing as a therapy. I asked her if there was anything that she had enjoyed during the writing group; she responded "the camaraderie, the sitting and chatting with the women." I believed she enjoyed the storytelling, the nurturing and support of and for each other. What she enjoyed the least was that she felt that she was "put on the spot, having to come and produce work." She didn't remember the impact of the writing or even the writing process itself:

> For me, the group, how it started as a Parent group, as a mother's group to get together and chat and have discussion about our children, our feelings, our feelings about our kids, sharing experiences with our kids, how we felt about them, sharing and talking was how I best communicate. When it came to writing, then it got into my own personal problems and inhibitions and that is where the communication broke down. That is why I got nothing out of it. It was then no longer sharing about my children. It entailed my own personal inhibitions and then the communication stopped for me. Because I had my own issues. Then it was no longer about my kids, it was about my issues.

These comments are very important to the understanding of writing as a therapy particularly within a group context. There are, I'm sure, other individuals who would prefer to write than to speak in a group. Yet, for those who have inhibitions and/or insecurities about their writing, they may, as Belinda, end up focused on the writing and not able to use it as a tool for problem solving, dealing with feelings, etc. Unfortunately, Belinda's initial objectives of finding better ways of dealing with everything, getting her head in a good place, learning strategies to cope with her life and finding ways to calm herself were not realized, at least in her memories and perceptions. It is of course, her memories and perceptions that are most important when discussing the benefits of writing as an effective means of problem solving and therapy, at least for Belinda.

I asked Belinda if there was a way that a writing program could be better for her. She responded first by proclaiming "I like to think that I am not afraid of a challenge and I have evolved." She felt that she would have been more comfortable with the writing if the writing activities were not as "vague and open-ended." She explained her style as follows:

> I work better to write if it is answering questions as opposed to just one topic. If there were a sheet with six questions and then fill in a paragraph for each question, that would be easier for someone like me. Two, three pages, I don't know where to start at that point. Maybe time factor was a problem. I think it was really just a fear factor for me.

Again, this is an indication of listening to the participant, listening to the words of the people being studied. I was actually concerned that I had been too directive in the written activities as much of the literature on writing groups suggests giving no

constraints, "just write." I was concerned that I organized the program more like a curriculum. Yet, Belinda needed even more structure and direction. It's also interesting to note that Belinda was concerned about her attention difficulties and individuals with attention difficulties often complain when trying to write that they don't know where to start. This shows the importance of dealing with each person individually and looking at their strengths and weaknesses, likes and dislikes. This also supports, in my mind, the importance of case studies and personal stories to answer research questions with true depth and clarity.

I found it so important to understand Belinda and what goes on in her head, so I asked her what happens to her regarding her ideas. She answered as follows:

> I am always in life, thinking of different ideas. In any given day, I could be thinking about my children, errands I have to do, things to do for my mother, just a whirlwind of things that have to be done, or things I want to do for work and somehow it just runs through my head. Maybe that is what happens with writing, ideas come to my head and I do not know where to start or finish, or certainly to start. I do not know where is the appropriate place to start a sentence or an idea and I do not trust my opinion enough, so I don't start. Or I do, and I rip out paper.

It appears to me that the sort of chaos in Belinda's mind could be alleviated or at least minimized with the incorporation of writing, even just using lists. Yet, Belinda seems to think that writing could be chaotic as she can't seem to organize a system for writing. She also repeatedly reveals again her insecurities as she speaks of not trusting her opinion and dealing with this by never starting or by ripping it up.

Belinda also discussed her "horrendous" memory, which she describes as getting worse. This of course was at least a little worrisome, as we continued our memory work together. What I then did was show Belinda one of the journal entries that she had given me and used it as a memory prompt. She read it to herself and appeared impressed by her writing:

Response to Memory Prompt

Well, what started out to be a disappointing evening turned out to be great. Our Saturday evening plans were ruined because my friend was sick. Instead of going to a favorite restaurant Charlie wanted to see a movie." Great some more quality time sitting beside him, not talking." But he promised we would talk in a restaurant after. We saw the movie "The Beach." This movie moved me. It's set in Bangkok, a place I've never been but, the people are such free spirits, I could relate to when I was young. Basically looking for fun and thrill. While watching this I suddenly began connecting with Charlie. I always knew that he frustrated me because he was most like me, most like my negative things. But all of a sudden I thought, were they all negative? I realized that it was time to have a heart to heart with him. At a different level not a lecture. But from my experiences and an understanding place. God knows my ways have not worked. This morning I sat with Charlie after he took his pill and started explaining my schooling-how bad I did-teachers and parents didn't know what they know today. He said he has an excuse not to do well. So, I said calmly, yes you could use this as an excuse but what would that get you? Where would you be? Anyways, from that point we had an amazing day. We went to the gym. Yes, my husband took my daughter so I could. We trained for 1 ½ hrs. He saw me in a different role; I was a trainer for a day. This has been an amazing day. I feel hopeful. I loved and liked him all day. Maybe we needed something like this.

I found this account of Belinda's memories most interesting as I wonder when people look at their writing what they remember. Do they remember the thoughts and feelings while writing the piece, the thoughts, feelings and events that were written about, some combination or nothing at all? I therefore probed a little further, asking Belinda what affects her when she looks at this journal entry now. Her reactions were as follows:

> I vaguely remember writing it. It comes to me more being in the movie and being in the gym with him, not writing it. I think that the reason why is because I was looking too hard for something to write. And that yes, I did feel this but I was looking hard all the time for something to write. What did I feel. I was just looking so hard for something to write as opposed to just getting up and expressing the feeling. Like I just shared before about how we have connected now on a level that is not really talking about that moment when I wrote it, but I can tell you honestly that over the past years that he is actually out of it that was such a negative experience for him that he is coming to talk to me. We are talking about who he is, where he is going. He is seeking out help and asking me to come with him as opposed to saying, No I am a big boy, I can do it on my own.

Belinda appears to be focused on the memory of trying so hard to write, yet her smile when she read it was of pleasure once again recalling a nice moment. Overall, Belinda's fears and insecurities heavily tipped the scales making it difficult for her to truly benefit from the experience. I believe that her attention and learning issues as well as her insecurities, need to be addressed and accommodated for before she can truly benefit from the writing experience. Or maybe writing as a therapy is not for everyone.

Mothers' Writings/Mothers' Stories: Summary

Themes emerging from the research.

When I began this project, the main objective was to look at writing as a means of therapy for mothers of children with special needs. The focus was on mothers' feelings towards reading and writing and the uses of reading and writing to problem solve and deal with emotions. These feelings were mostly positive and the mothers' experiences of problem solving and dealing with emotions were quite apparent. They reported using reading and writing to help them remember, organize thoughts, problem solve, vent, and deal with emotions. Their stories differed, their ways of writing differed, but the themes were consistent. I discussed the themes in two categories; themes around mothering a child with special needs and themes around feelings derived from writing.

Themes around mothering a child with special needs.

I chose to begin this summary with a short narrative written collectively by the mothers, summarizing their own feelings about what it is to be a mother of a child with special needs. I will follow that by an analysis and discussion of the most common themes obtained through the systematic study of the mothers' writings.

Collective Writing

Throughout these writings one cannot help but sense the incredible love of a mother for her child. Notions of beauty, uniqueness and special joy are almost always mentioned in connection with the child coming into the world. The birth of a child is a momentous occasion. We wait expectantly as the child grows hidden from view. We try to imagine the gender, the special features of this yet unborn person. Emotional bonds deepen long before we see the newborn's face.

> Suddenly shock, grief and despair burst in upon a mother's world the first time she realizes that something is wrong. There is a reluctant acknowledgement of imperfection followed by troubling worry. Who has stolen her child's beauty and wonder? Who has robbed her of her special joy?
>
> Our stories describe a long, winding path filled with the many emotions and challenges of life with a special needs child.

Over and over again, I read and heard the same fears, feelings, thoughts, concerns and questions. I recorded these recurring themes and found them in all of their stories, as well as in my own stories, in published autobiographies written by mothers, in the stories I hear day after day in my clinical practice and in the stories I tell as a mother. Many of these themes have been highlighted in the literature review, some of these were expanded upon by my participants and some less recorded themes were presented as well.

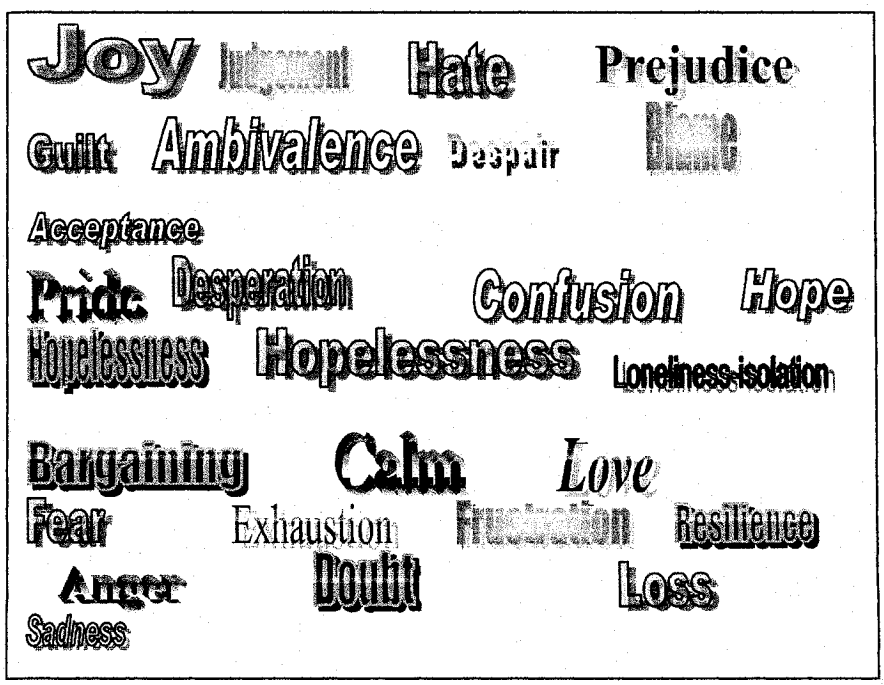
After reviewing all these data sources, the following themes emerged.

- worry about the child's future
- devastation over the child's limited potential or what appears to be limited potential
- feeling of being a "bad mother" and desire to be a "good mother"
- feeling loss of control, feelings of anger, frustration and worry
- feelings that these worries are being dismissed
- incongruence between the thoughts of the mothers and those expressed by the professionals
- feeling totally overwhelmed
- feeling that mothering is a 24/7 job and nobody else can do it. This feeling was described as sometimes coming from within and sometimes coming from outside sources.

- feeling stressed, tired, run down, and under appreciated
- feeling that they are running a race, that their child is behind and if they do not run faster and faster they will never catch up
- wishing that their child was like everyone else
- feelings of judging themselves and of being judged ("so many courts along the way")
- feeling very vulnerable
- feeling like "a big, ugly, monster mom," always being the big mean mother.

I compiled all the themes, positive, negative, and often conflicting, and presented the following visual representation to the mothers during the post-project interviews. They responded with enthusiasm and some with sadness over the many negative emotions. They all said that they had experienced most, if not all, of the themes presented, though not all at the same time.

Feelings around mothering a child with special needs.



Some researchers write about their concerns regarding "smoothing" or Hollywood's happily-ever-after theme (Connelly and Clandinin, 1990). This was certainly not the case in my experience, although there was a tendency to "smoothing," as the participants often ended with "but I love him so much" or "it is always worth it." The participants in this study were very open and even more precisely, wanted the difficulties and the painful issues to be portrayed in their stories. The mothers wished for happily-ever-after, but rarely wrote that way. The "smoothing" was often a result of feelings of guilt, not wanting to give the impression that they were complaining about their child. However, it was more often arising out of true experiences. These mothers truly do love their children that much and do believe it is worth it. They reported feeling joy when they were able to write about happy moments and breakthroughs no matter how large or small.

Themes around writing.

The following themes emerged from the anecdotal notes when discussing the mothers' feelings about their writings and the writings of others.

- Reading the work is more emotional than writing it.
- Writing often evokes feelings of self-pity, but more often the power of opening wounds and then healing them.
- Writing helps make thoughts deeper, clearer, and more descriptive.
- Writing helps to "force things out of the writer's head," expressing them instead of keeping them inside.
- Writing eliminates the "bogged down" feeling of being overwhelmed.
- Writing unsent letters, in particular, relieves pressure and strong emotions, bringing them from head to hand.
- Poems use less words to get to the point and present feelings as images.

Through the words, whether written or spoken or both, we can see that there are recurrent themes: those of many, many feelings around mothering a child with special needs: feelings that are positive, negative, ambiguous and often conflicting; feelings that come and go; some that change, some that intensify. We also see that writing seems to help these mothers recognize and deal with these feelings.

Chapter 6: Discussion

In this chapter, I summarize some of the key findings of this thesis and go on to discuss the importance of the researcher including a self-study as an integral part of his or her research. I link the findings of this study to the literature on the mothering debate, with a particular focus on the writings of the last two years. Finally, I discuss the contributions of this study, its challenges, and recommendations for future research.

Key Findings

In studying the therapeutic aspects of writing for mothers of children with special needs, there are several key findings. Perhaps the most important one is that all of the participants spoke or wrote of how they had enjoyed sharing and confiding in the group, whether it was in the form of writing or in the form of speaking. They expressed how they were all looking for support. They wanted to get their "heads into a good place." They reported feeling refreshed after the sessions. They felt that they were now inspired to use writing to communicate letters to the teachers, to make lists, and to organize themselves better. Their inspiration for writing was strikingly illustrated when one of the mothers suggested writing as part of the post-project interview. This was an unexpected secondary gain which facilitated and enriched the information I collected. Many of the participants equated writing with intelligence and used phrases like "respect for the written word." This was highlighted in Belinda's story, where her perceived difficulties with writing made her feel less intelligent. Many of the participants talked of writing in their heads, but not always having the time or ability to put it down on paper. Many of these themes highlighted the importance of looking at the mothers' profile and the

mothers' needs when designing such a program. Many of them felt that writing was deeper, clearer and more descriptive than speaking.

A second finding focuses on what I would describe as mothers as advocates. The mothers had what they described as a burning desire to have others read what they wrote, so that perhaps their words could alter the misconceptions and false perceptions of those on the outside. While my focus throughout has been on the therapeutic aspects of writing, I also see that the mothers' writing revealed a connection between writing and advocacy. It became quite apparent that there was an incredible need for mothers to advocate for their own children and to advocate for mothers and children with special needs in general. There appeared to be a pressing desire to have professionals, educators, doctors, psychologists and others understand what these parents, particularly mothers, go through and to hopefully be more empathetic in their future interactions with other parents. Trying to help others understand, was perhaps the most consistent and pervasive goal.

Van Manen's (1990) description of a tendency to break down life into new abstractive fragments that are of little use to practitioners was precisely the concern of many of the participants in the study, and certainly a concern of my own. In their discussions and in their storytelling and writing, particularly the writing of letters, the participants in the study were driven by their feelings that practitioners in the educational and medical fields are often totally unaware of the reality of being a person with special needs. They wanted to use words to paint a portrait of a child going through the medical and educational mazes. They hoped to also illustrate what one goes through being a parent of a child with special needs (i.e., going through massive, very confusing labyrinths, with many blockages). The participants were driven to write and to try to get

their writing published in a belief that perhaps some medical personnel, teachers, and therapists would read their words and just maybe become more sympathetic, empathetic, understanding, communicative, and interactive. This is also in line with the introduction by Dr. Marion, a physician, to the book *From the Heart: On Being the Mother of a Child with Special Needs* (Marsh, 1994) where he explained his new level of understanding after reading the book.

Seligman and Darling (1997) suggest that the more parents interact with their children, the greater their commitment to the child's welfare. They believe that developing an emotional bond between parent and child is a strong catalyst to parent activism. They recognize that parents of children with special needs meet other parents, often during medical treatment or educational programs, often exchanging stories and learning that they share similar problems and experiences. They suggest that when parents interact with each other, they share information about techniques that have worked and they may begin to realize that authority can be successfully challenged. This was the experience which I initially discovered in my pilot study, inspiring me to include a writing activity on writing an advocacy statement or paper in the actual project. The idea was quickly embraced by the group, with their strongest comments involving whether they could actually send their suggestions to the appropriate agencies.

Cullinan (1997) suggests that an incentive for the participants in her study was the idea that their stories were worth recording for posterity. The participants in my study expressed a need to know that their writing was recorded. However, they also expressed a great need to know that their writing would actually be read, as soon as possible, and by a much larger audience. They hoped that their words would make a difference.

A third finding relates to the need to deepen our understanding of the parent-professional interaction. Incongruence of thought between mothers and professionals in either direction, be it over- or under-diagnosed, is an issue which has begun to receive considerable attention. Efforts to improve parent-professional communication and collaboration is a goal shared by the medical, educational, and social systems in North America (Seligman and Darling, 1997). The question is, can and will these admirable goals be realized?

The mother's feeling that something is wrong, which is not addressed or taken seriously enough, is a recurrent theme when discussing relationships between parents and professionals. This was seen in Sally's writing, when she described her insistence on tests for her son Bobby, as well as in Chantal's angry letter to her doctor, because he didn't listen. Other feelings seen in the mothers' writing were that professionals were quick to blame, to diagnose without enough information, to patronize, minimize, differ, not listen, and seem to not care. Issues of fear, lack of trust, anger, and blame were amongst the many feelings expressed. The mere fact that these fears, frustrations, and feelings came out in each and every one of the participants' writings in the focus group, as well as in the project group is a strong message. It is a message that can be seen as well in the popular literature, in some of the professional literature, and in all of the published autobiographies written by mothers. It is a message that I experienced twenty years ago, when my child with special needs was born, and as recently as a few weeks before this thesis was submitted. Parent-professional interaction is under-valued by professionals, and rife with distrust, frustration, and resentment on behalf of the parents. There is still much research to be investigated in the future, to drive educational and clinical practices

to recognize parent-professional interaction as an effective tool in facilitating diagnosis and treatment.

Self as Participant: Learning to say "I"

During this project, I realized that studying myself gave me the insight to better understand the participants in my study. I identified with their thoughts, teachings and perceptions. This process of self-analysis offered me insight that I believe could never have been understood as well without hearing my own inner voice as I composed thoughts and retrieved memories and then wrote my thoughts on paper and then read them.

It was my own personal experiences that initially had me wondering how memories are encoded and filed in the brain and how they are retrieved. Why, for instance, do I have different reactions to the same stimuli? For example, when I hear or see an ambulance I have different reactions. Sometimes it doesn't move me at all, or I may have a small reaction, feeling a slight concern just knowing the ambulance is carrying someone sick or injured. On other occasions, an ambulance siren can elicit strong feelings of sadness and evoke vivid flashes of the many times my own child has been rushed by ambulance to the hospital. Why then are memories retrieved in different ways by different individuals or even by the same individual at different times? Kotre's (1995) suggestion of using many sensory modalities to prompt memories is consistent with my ambulance analogy, where the sound of the siren and the sight of the vehicle elicit memories and emotions. Sometimes I think certain physical and sensory factors may be related to how I react emotionally. For example, how close am I to the

ambulance? Is one sensory modality or multiple modalities being stimulated? Is the vehicle going fast or slow? Are the lights flashing? Are they putting someone into the ambulance as I drive by? I believe that these factors may influence the way that memories are released, felt, and experienced. These reflections have led to more questions, which leads to my interest in continuing this kind of work.

Different memory prompts don't always elicit the memory that we may have expected. This was evident in the reflections of my participants as well as my own personal reflections. For example, Wanda's feeling when she looked at the clay mould of her son's hand, which was a symbol of his disability. Chantal's thoughts while looking at her son's baby bottle as she recalled that at that time, all was fine. For each of their experiences I had experienced a similar memory trigger and response. I was stunned when I pulled out a picture of my child, taken before she was diagnosed, and noticed that her smile was asymmetrical. This was first observed while I was doing my Ph.D. I had viewed the same picture at least a hundred times before, yet prior to this all I had seen was an adorable baby. For me that picture now symbolizes her medical condition, similar to the way Wanda's son's handprint symbolizes his disability for her. I often look at one specific picture of my children, taken before my child with special needs was diagnosed. A feeling of sadness arises as I often think "that was before, when all was fine." This felt quite similar to Chantal's memories, triggered by her son's baby bottle.

When discussing the process of reading and writing, I once again noted many similarities between my thinking and actions and those of the participants in the study. I too experienced composing letters and narratives in my head, but often not getting them to paper as Chantal described. I reflected upon my experiences with doctors, teachers,

colleagues, family and friends, and was amazed by the similarities I felt with the participants' stories. I could feel the emotions. I could understand the way memories are retrieved differently at different times and in different ways, with different thoughts, sensations and perceptions. But how could I know that the ways my thoughts and memories appear to function are similar to those of others, particularly others undergoing the same phenomenon, if I didn't question them and read their thoughts. I believe both processes, self-reflection and comprehensive study of others, are necessary to really understand the human mind. In conclusion, I realized the importance of a researcher as participant.

Cullinan (1997) also wrote along with her participants. She believed that there was no better way to show her sincerity and belief that writing was a worthwhile activity. She reported that each time, she shared her own work, she knew first-hand why the others kept coming to the sessions. She understood how good it felt to be listened to and not judged after having experienced this process, I now truly believe that there is no way one can understand these feelings without experiencing them. They cannot be as clearly and easily described.

Even though I realized its importance and even necessity, I was initially resistant, apprehensive and opposed to being a participant in my own study. My rationale for this opposition was based on my concern about holding more than one role at the same time (i.e., researcher/practitioner/participant), and my strong conviction that this is not just my story-it's my daughter's story, my husband's story, my family's story. However, as I read the literature, I began to realize, as my committee has suggested, that there would be a major hole in my study if I did not situate myself in it.

Richardson (1994) writes that "writing from ourselves should strengthen the community of qualitative researchers and the individual voices within it, because we will be more fully present in our work, more honest, more engaged" (1994, p.516). She encourages researchers to nurture our individuality and put ourselves in our own texts. Van Manen (1990) suggests that the topic a researcher chooses to investigate usually reflects something personal or professional. I can't imagine how one can truly understand the complexities of certain situations without having experienced them, especially in the case of mothering a child with special needs. At some point in the project, then, I became one of my own participants. This is very much in keeping with Van Manen's approach. When researching it, Van Manen suggests that a phenomenological question asks what a human phenomenon or life experience is like. That is, what is it like to ***be.*** Van Manen further suggests that our own experience is a good starting point for research since we can access our own memories in a way that no one else can.

These thoughts are very much in line with the work of Daphne de Marneffe (2004), a clinical psychologist who believed that if she could understand some of the social and psychological content of the feelings she was experiencing as she became a mother for the first time, then perhaps she could help other women becoming mothers to find satisfaction in their lives. She described her book, *Maternal Desire: On Children, Love and the Inner Life*, as a personal book but also one which contains research and scholarship on mothering. She expressed that her goal was not simply to present ideas but to also give the reader a certain kind of experience:

> The very act of writing the book was integrating for me, a process of knitting together different aspects of myself. It was fully anchored in the

> day to day of caring for babies and young children but it also grew out of my interest of acting as 'participant-observer' that is immersing myself in the emotions and experience of the moment and being able to stand back and reflect on it. (2004, p. 3, Reading Guide)

This idea of using her knowledge and her research, looking at professional and popular literature, as well as reflecting on her own feelings and perceptions, is in line with what Van Manen and others recommend, and also in line with my ideas. I took comfort in reading about another psychologist who had the courage to look inside herself, at her own feelings and to write about it. DeMarneffe explains that in an attempt to address a whole person, it's similar to what we do as parents, and it is not unlike what therapists do in therapy. She discusses how we try to help our children or our patients to become aware of their feelings and to have the greatest possible freedom in thinking about them and making good choices in respect to them. One of her central goals was to examine the way in which "intellectual ideas and cultural trends infuse our personal experience of motherhood."

Mauthner and Doucet (1998) explain reflexivity as the reflections upon and understanding of our own "personal, political and intellectual autobiographies as researchers and making explicit where we are located in relation to our research respondents" (p. 121). This is so true. In my case I am constantly reflecting about where am I located and how I feel in my different roles. Although this is at times difficult, I believe that it allows me to be a better perspective taker, understanding from the point of view of parent, educator and psychologist. Wearing so many hats enables me to reflect and understand the position of my child(ren)'s teachers and doctors. In my professional

role, I can better understand the mothers with whom I work with and help them to better understand their child's teachers, therapists, doctors and even their spouses, extended families and friends. As a result of my recent experiences with writing and storytelling, I'm no longer afraid to tell my clients and my students personal stories to help them heal and/or learn. The feedback on this approach has been overwhelmingly positive.

Mauthner and Doucet further suggest that we factor our own assumptions and views into our interpretations of others' writings (their stories). I am aware that these elements might influence my interpretations. My personal self relates to maternal feeling of the need to advocate, and of the need to nurture, to make the proper decisions, to battle anybody or any institution who is not prepared to give my child(ren) what they need and to the additional feelings of responsibilities that come with having a child with special needs. My political self is one who is very pro-integration (inclusion). I believe in including and accepting all children and all people for who they are. This probably influences the way I interpret some of the mothers' writing, particularly with regards to advocacy. My theoretical self probably considers areas of education when I am interpreting the participant's feelings. Further, my most recent theoretical knowledge in the areas of feminist research, in maternal thinking and research, and in advocacy come into play when interpreting each piece. This type of exercise opened my eyes to the numerous aspects of a text and to the complexities and the richness of this kind of work.

Finally, I look at how much my experiences as a mother of a child with special needs lead me to a place where I could bridge my personal and my scholarly quests at understanding. When my child was first diagnosed, I took an academic leave of absence to take care of her. This choice was strongly frowned upon by the department where I

was a student at the time. The doors were closed forever and I later saw this as a serious career derailment. However, years after that, I found what for me was the road less traveled. I realized how exciting it was to be given the opportunity to be part of the paving of new roads. I embarked on a new and exciting voyage. My life experiences had brought me what I know and I believe were better voyages. During my Ph.D. program, I took a number of courses to learn about qualitative research and interpretative inquiries. I used many new and creative means to truly understand the phenomenon I was studying.

Two writing activities that were particularly revealing were a poem I wrote to summarize the writings of the participants in my study and two collages I made, comparing mothering a child with special needs to other mothers. Both of these activities, which tapped on my creative side, were very revealing. As I was working, studying and raising a family, living the life written about in many of the recent texts on mothering, with the added dimension of the child with special needs, and the additional demands and requirements, I worked through these writing activities very quickly. When I reflected on these creative products, I was amazed.

The poem that follows was written for a presentation on qualitative inquiry of the written work. It was to be a personal reflection guided by collective thoughts.

Some days I feel
As if I may wilt
As I suffer all the ailments
Of a mother's guilt.

My child has no problems
As the truth I tried to deny
Reality slowly seeped in
As I questioned and questioned why?

The feelings overwhelming
I felt so very sad
As bubbly inside my heart
I felt so angry, so very mad.

I love my special child deeply
But my life will never be the same
Did I do something wrong?
I looked for reason to myself blame.

Now I continue to question myself
Each and every day.
Only the very best
For my children I do pray.

My mother mind & mother heart
Is full of guilty stuff
As I ask each and every day with
Did I do enough?

Did I speak softly enough
Did I reinforce & praise
Am I doing all I must
To this child raise

Do I learn enough
As I read & read
Do I protect this child
Not let her feelings bleed.

Do I make good choices
With doctors, therapists & the school,
Do I think before
I choose & impose each rule

Even though I live each day
With worry & with guilt.
This child makes me feel so tall
Like I'm standing on stilts.

I treasure every day
And every precious minute
I feel the joy & pride
When they talk, listen, jump or sit

The feelings of sadness & guilt
Are truly very mild
Compared to the love and joy
I gain from my special child.

When I reflected upon the messages in this poem, I saw the same thoughts, feelings and perceptions spoken and written about by my participants, my clients and in the literature. I saw denial, guilt, anger, love, sadness, worry, joy, pride, and blame. I read "my life will never be the same", "did I do something wrong?", "do I protect?" What an amazing message to other mothers and to professionals and educators.

For the collage activity, I used my creative side at first, without using my thinking, logical side. I tore out magazine pictures and then divided them into two piles. I then made two collages, one to portray mothering, the other to portray mothering a child with special needs. I write now with a little embarrassment as although I initially thought this writing activity would be fun, I wasn't expecting much. I was literally "blown away" by the results. The collage on mothering showed love and nurturance; a man kissing his wife's pregnant belly, a mother reading to her child, hugs, smiles and kisses. The collage of mothering a child with special needs showed pictures of a woman in a suit, holding a briefcase, standing in front of a building, and a woman holding up a mop ready to fight and other such images. The message was work, advocacy, fighting and so on. What a powerful message. This exercise is consistent with suggestions made by Capacchione, (2000) who wrote *The creative journal for parents: A guide to unlocking your natural parenting wisdom.* My experiences helped me to further understand and gain insight into the phenomenon I was studying. Perhaps, equally important, it showed me the importance

in using both hemispheres of the brain when studying the human mind in all its complexities.

The Mothering Debate Continues

When I started this study several years ago I tried to explore every possible angle on mothering, with particular focus on mothers of children with special needs. As I come to the end of writing this dissertation, I find that the mothering debate continues ever more intensely. Mothers are investing more and increasingly judging themselves on the success of their children, as measured by the children's skills, talents and intellects. More and more literature is being devoted to understanding motherhood in all its complexities, yet rarely touch on the impact on mothers of children with special needs. I can't help but worry about the overwhelming pressures that must be felt by these mothers, who must deal with these same issues (ex., stay-at-home vs working, making the right choices, driving the child to success) but whose measurements of success for their children, and by extension for themselves, may be very different from society's expectations.

Warner (2002) in her book, is eloquent in pointing out how much time mothers invest in trying to raise "the perfect child." She suggests that the judgment of whether one is a good mother is based on the success of her child. Once again, what does this do for the mothers of children with special needs? Warner was one of the only authors that I read in my review of non-academic literature who paid any attention to this special population. In her nearly 300 pages describing interviews and stories from mothers, she devoted approximately four pages to this topic. She described an interview with a mother who was a pediatrician. Her son had been diagnosed with low muscle tone and sensory

integration issues. She described this mother's relief as it was easier to deal with this diagnosis than with feeling like "a bad mother who could not control her child's behaviours." I believe that the following quote from Warner's book poignantly describes the whirlwind of a life that many mothers go through with their children, particularly children who suffer from illnesses and/or disabilities. She describes it like a rapid march which is hard to keep up with. This "march" was portrayed in a number of the mothers' writings in my study as well.

Ellison (2005) wrote *The Mommy Brain: How Motherhood Makes us Smarter* in an attempt to examine how motherhood can basically make the brain a more complex organ, thereby contradicting the myth that having a baby means "checking your brains at the delivery room door." Ellison and her husband first became parents while living in Rio. When her children were one and four years of age, the family moved back to the United States, specifically the San Francisco Bay area. She describes the transition from the Brazilian model of nanny-supported childcare to contemporary U.S suburban style. She is not the only author to describe "culture shock" and disappointment when comparing motherhood in Europe and in North America. However, these were comparisons of affluent people and therefore do not compare mothering between continents in other S.E.S. groups.

In a Newsweek article (January 2004), Anna Quindlen, a Pulitzer Prize winner and successful author, describes her reproduction transition thusly: "It was as though my ovaries had taken possession of everything. Less than a year later, an infant had taken possession of everything else" (Quindlen, cited in Ellison, 2005 p.5).

This overwhelming feeling that motherhood seems to cast over a woman, mind and body has been joked about, spoken about and written about. I frequently wondered as I read the literature, what kind of total invasion must be felt by mothers of children with special needs. The participants in this study had much to say and write about it. Some have described it as feeling as if they had landed on another planet, others have used words such as "forging a war against it" and finally the mothers expressed feeling completely overwhelmed, confused, exhausted and totally depleted.

Quindlen's negative self-judgments in light of all her professional accomplishments appear similar to contradictions experienced by mothers of children with special needs who have advocated, worked tirelessly for their own children and/or many children with similar plights, read, wrote, researched, fought and sometimes even won, yet reported feeling weak and non-productive. These issues raise attention to mothers' feelings of inadequacy and lowered self-esteem. If Quindlen expressed it, while raising apparently "typical" children, then what about mothers raising children with special needs? This contrast in one's feelings of success versus feeling of being "taken over - mind and body" is one expressed by many mothers, often mothers who hold careers in executive and/or professional positions.

Ellison, like most writers who focus on the history of mothering, discusses John Bowlby's attachment theories and the relief mothers felt around 30 years later when reading the book *The Nurture Assumption* by Judith Rich Harris. She cites numerous studies which attempted to demonstrate that there are a great many variables which influence child development, beyond nurturing by the mother. Ellison explains however,

> ... the relief Harris hoped to offer didn't last long. If anything there has been an increasingly fierce debate in the early years of the new millennium, over minimum mothering that children need, and scientists are entering the fray more determinedly than ever before. (2005, p.192)

Keahey and Schnitzer (2003) edited a wonderful collection of narratives and poetry focusing on many of the dilemmas faced by mothers in academia. The book titled *The Madwoman in the Academy... 43 women boldly take on the ivory tower* is a comprehensive collection dealing with many issues, and many humourous tales such as the mother who hung on to her Ph.D. thesis in a green bag, which the author described as "birthing a dissertation", as she traveled through the stages of labour and delivery. The authors talk of holding events to open dialogues on conflicts between the personal and the professional for woman in the academy. Women had similar stories to share such as sick children during exams, and hiding the news of pregnancy from graduate chairs.

Abbey and O'Reilly (1998) edited a collection of articles written by teachers or researches in the field of education. They explored the "hybridity of maternal subjectivities," highlighting challenges encountered by mothers in the workplace. Managing child emergencies and caring for sick children were among the issues mentioned. They discussed how women's lives are still being restricted by motherhood even as women have become more independent in their careers.

Many of these stories reminded me of my own. And once again, made me think about how even more complicated the mother/professional conflicts become when the child has special needs.

Contributions of this Study

When I set out to do this project my main objective was to look at mothers who have children with special needs and the way they could use writing as a therapy. I believe the study has contributed to a deeper understanding of the uses of various forms of writing for these mothers. Through my analysis of the writings as well as in-depth interviews, both oral and written, I was able to gain a deeper insight into the extensive thoughts and emotions that these mothers experience day after day, year after year. A number of themes dealing with the stages of mourning as well as other emotional reactions were consistently evident. The information obtained in this study was also helpful in understanding other inter-related processes such as storytelling, reading one's writing aloud, listening to the writings of others, and exchanging ideas and feelings, both similar and differing. This study also looked at memory work in two ways: mothers looking at memory of early events with their child as well as reflecting on the group experience over a year after the completion of the program. The similarities in the way different prompts helped to trigger these memories and the way the memories were played out in people's minds was quite revealing. I believe understanding these common threads may contribute to illustrating the importance of using memory work in this kind of research.

The first of two unexpected areas where I believe this research has contributed to the knowledge in this field of study is its detailed description of the intensity of these mothers' needs to tell their stories and to advocate for themselves and for others. Secondly, although I initially believed that the value of qualitative research had previously been well established, while conducting and analyzing this study it became

apparent (a) how much work is still necessary in this area (i.e., gaining respect for qualitative research in areas such as psychology and medicine); and (b) just how powerful a research tool it actually is. Although I hesitate to use the word "reliable," I find it encouraging to see how the same stories, the same feelings, the same memories, recalled in the same way, were told and written about over and over again. I believe that this is an important finding in advancing our knowledge of both the practical and emotional lives of mothers of children with special needs, and the power of the written word for therapeutic as well as for research purposes.

Challenges in Conducting this Research

The challenges which seemed to be the most "handicapping" for this study were completely intertwined with the nature of the study and the nature of the participants. One variable was attendance/participation. This was seen in a tendency of the individuals to miss sessions, the attrition rate and the inconsistent quantity of written work handed in, particularly with respect to the questionnaires discussing each session. The participants continued to exhibit considerable interest in the project, which was noted in their calling to say that they would be absent, rather than just not showing up, their regrets that they would be missing sessions, and their comments after they returned from having been absent. These mothers all had at least one child with special needs, so they were frequently overwhelmed with the physical, emotional and time constraints placed upon them. They would be ready to come to a group, but would get a call from the school that their child was sick or acting out, or they were just too exhausted from having been up all night worrying or caring for a child with special needs. These absences contributed to

some members feeling that they had given up their time but others were not participating with the same motivation and intensity. Some of the members felt that this had a negative and/or de-motivating effect on them.

One mother brought her children very often, which was quite disruptive and changed the dynamics of the group. The other participants found it difficult to concentrate and yet reportedly felt horribly guilty to say anything about this. At times, the mothers reported that they felt uncomfortable coming to a session if they had not completed the work and felt they were taking up the time of the other mothers. Some participants explained that once they started writing, they were worried that they would not have enough time to finish. Others felt they had no opportunity to write and they needed more motivation, more time and more structure. Many of the comments were indicative of the realities of their lives and feelings that accompany such realities – feelings of lower self-esteem, insecurities, guilt and blame, all emotions which are an integral part of the profile of a woman who is mothering a child with special needs. Finally, either because of feeling rushed and/or insecure, many did the work and then made comments such as: "Let me fix it up and bring it next time" and some writings were often not handed in, despite significant encouragement and endless unsuccessful efforts to explain that the writing was not being judged.

Another limitation of this study was that many of these mothers, as the literature suggests, were going through different stages of mourning and at different times. Therefore at times, they were totally "on" and ready to contribute, to tell or write their story, to share and to be supportive of the others. However at other times their feelings of guilt, anger or sadness seemed to get in the way of their being able to fully participate.

The different members, being at different stages of mourning, contributed to constantly shifting states of mind within and between individuals, which ultimately altered the dynamic within the group. One member would be just feeling better and another would have just become very sad or angry. One would feel guilty about not having written anything or feel low about their inability to write, when another had just experienced a writing explosion. On the other hand, the benefit of being at different mourning stages is that they were not all depressed, confused or angry at the same time and could therefore help and support each other. If one member was really down, frustrated, furious, some of the others may have been in the acceptance stage, where they could guide and support or just be there for the needy one.

When designing the study, I weighed the pros and cons of structuring the writings versus having the participants spontaneously write and discuss their writings. Based on the literature discussing writing groups, I had concerns that I was being too directive and I deliberately tried not to be. Yet after the completion of the study, the participants often commented that they liked the direction and would have preferred even more than I had offered. A challenge in this kind of study is finding the right balance-inspiring and directing the participants' writing without stifling their creativity and spontaneity.

Finally, I worry that I may have placed extra pressure on the mothers, by asking them to write at home. If the group had been designed in such a way that all writing was to be done solely within their sessions, it may have alleviated some or all of these challenges.

Implications for Future Research

There are a number of areas where I believe this type of research can make strong contributions. I believe that the findings in this research strongly illustrate the importance of writing as a therapy, yet my literature review found minimal research on writing groups. The literature focused more on how to organize a writing group than discussing the various aspects of the writing group and the impact that this may have on the individuals participating. Furthermore there appears to be little research on writing as a means of therapy for mothers of children with special needs individually and/or in a group. There should be further research into writing as a therapy, with attention paid to the different types of writing (i.e., letter, poem, etc.). How this may help mothers with children of special needs in the therapeutic domain and in improving problem-solving strategies should be investigated as well. Mothers writing to further understand the phenomenon of raising a child with special needs would be useful for problem solving, emotional release and advocacy.

Research into mothers using writing to help them advocate for medical evaluation and treatment, for education and for research, is definitely an area begging for attention. When individuals are seeking help from medical and other health care professionals, they are asked to complete forms and are requested to participate in an oral history taking, to provide the "story" of the child. Aspects of writing as a way to communicate that story, as well as the feelings around the stories should be investigated. Looking at questions such as whether this would facilitate diagnosis, treatment and more effective interactions would be very interesting. Communication booklets between parent and teachers have been utilized in many private and public schools. However, more research into this

method of communication between parent and teacher, and how it may facilitate better interaction, better communication and perhaps more effective education for these children would be helpful.

My experiences with creative analysis as well as my observations and analysis of the participants in this study as they experienced similar writing activities, made me keenly aware of the importance of tapping into our creative side and looking at problem solving and self analysis in this way. Peterson (1999) did a study comparing the writing products of individuals, contrasting these written works using one's dominant and non-dominant hand. Further research into this area would be most interesting and valuable.

Finally, as frequently mentioned, the literature on mothering has left a huge gaping hole in the area of mothering a child with special needs. An historical analysis of the area, as well as an historical analysis of parent and teacher roles in educating these children and parent/ professional interactions must be addressed. Continued research focusing directly on this population is essential in furthering the work needed to heal, nurture and educate mother and child.

The theme of writing and seeing one's thoughts reflected and changing was very apparent to me, as I wrote and re-wrote these mothers' stories. Every time I sat down to re-write, re-read and make changes to my analysis section, I found myself noticing more themes, more reflections, and more important elements to the understanding of this phenomenon. This made me reflect upon the use of writing in communicating between parents and teachers. If they were to write to each other, reflect upon their writing, and re-write before sending, it might facilitate the thought processes, increase understanding of the other person's perspective, and result in more effective interpersonal

communications. I would like to see the school year begin with parents writing a "this is my child" letter, introducing the child's strengths and weaknesses, likes, dislikes, and needs. Then instead of, or at the very least in addition to, the complicated report card with elaborate, ever-changing grading systems, the teachers could write a letter to parents, reviewing and describing the child's progress. The children could write where possible to parents and teachers, speaking or drawing could replace writing. A study of whether this would facilitate parent-teacher relationships and child success would be most interesting.

This research has led me to believe that we must further investigate the many uses of writing, not only to help mothers deal with their feelings, but also to look at the ways in which mothers' writings can be used to better understand the needs of the child and the family, and to facilitate an increased knowledge base in educational and medical practices for this very special population. In my review of the literature on mothering, I was struck by the constant references to mother-blaming, maternal ambivalence, good mother/bad mother themes, intensive mothering, and mother guilt. The participants in my study spoke and wrote about these same issues. Writing helped to identify these problems. I believe that writing can help to solve them.

Epilogue

It is the year 2017 and major progress has been made in the area of parent/teacher communication and parent/doctor communication. Mothers are being listened to and are considered part of the team in the educational and medical forums as well as with other health professionals (i.e., social workers, psychologists, and other therapists). Mothers are no longer being blamed for their child's problems but are rather being validated for their concerns and being listened to.

Mothers are communicating with these professionals, often in writing and the result is more clear and effective communication with better diagnosis, treatment and educational plans and less anxiety, anger and conflict. It is the 10th anniversary of the inception of an organization called "Mother Writes", where mothers who are professional writers and mothers who like to write for the sake of writing, get together to share ideas and to drive the research in the field of education and medicine and continue to advocate for their children and for the children of others (i.e., for their rights). There is still a long way to go, but at least the parents and professionals are working together and the children with special needs are the winners.

References

Abbey, S., & O'Reilly, A. (Eds.). (1998). *Redefining motherhood: Changing identities and patterns*. Toronto, Ontario: Second Story Press.

Adams, K. (1990). *Journal to the self: Twenty-two paths to personal growth-open the door to self-understanding by reading, writing, and creating a journal of your life.* New York: Warner Books.

Agnes, S. M. (1946). Bibliotherapy for socially maladjusted children. *Catholic Educational Review, 44,* 8-16.

Amosun, S. L., Ikueson, B. A., & Oloyede, I. J. (1995). Rehabilitation of the handicapped child-What about the caregiver? *Papua New Guinea Medical Journal, 38(3),* 208-214.

Arendell, T. (1999*). Mothering and motherhood: A decade review*. Center for Working Families, University of California: Berkley.

Aronie, N. S. (1998). *Writing from the heart: Tapping the power of our inner voice*. New York: Hyperion.

Atkinson, R. (1998). *The life story interview*. Thousand Oaks: Sage Publications.

Baker, B. L., & Heller, T. L. (1996). Preschool children with externalizing behaviours: Experience of fathers and mothers. *Journal of Abnormal Child Psychology, 24(4),* 513-532.

Beck, M. (1997). *Breaking point: Why women fall apart and how they can re-create their lives*. New York: Times Books.

Beck, M. (1999). *Expecting Adam: A true story of birth, rebirth, and everyday magic.* New York: Random House.

Beck, M. (2001). *Finding your north star: Claiming the life you were meant to live.* New York: Three Rivers Press.

Bell, R. Q., & Harper, L. V. (1977). *Child effects on adults.* Hillsdale, NJ: Lawrence Erlbaum Associates.

Bentley, R., & Butler, S. (1988). *Lifewriting: Self-exploration and life review through writing.* Dubuque, IA: Kendall/ Hunt Publishing Company.

Bernstein, N. R. (1978). Mental retardation. In A. M. Nicholi (Ed.), *The Harvard guide to modern psychiatry.* Cambridge, MA: Harvard University Press. Cited in Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children: A systems approach to childhood disability (2nd ed.) (pp. 89-90).* New York: The Guilford Press.

Bibliotherapy (1982). *Fact Sheet.* Urbana, IL: ERIC Clearinghouse on Reading and Communication Skills. [ED 234 338]

Bowlby, J. (1958). *Can I leave my baby?* London: National Association for Mental Health.

Bracher, M. (1999). *The writing cure: Psychoanalysis, composition, and the aims of education.* Illinois: Southern Illinois University Press.

Britton J., Burgess, T., Martin, N., McLeod, A., & Rosen, H. (1975). *The Development of writing abilities.* London: Macmillan.

Brooke, R., Mirtz, R., & Evans, R. (Eds.). (1994). *Small groups in writing workshops: Invitation to a writer's life*. Illinois: National Council of Teachers of English.

Bruner, J. (1975). Language as an instrument of thought. In A. Davies (Ed.), *Problems in language and learning.* London: Heinemann.

Bruner, J. (1990). *Acts of meaning.* Cambridge, MA: University Press.

Butler, S. (1992). Literacy through lifewriting. *English Quarterly, 24,* 33-41.

Buxton, Bonnie (2004). *Damaged angels: A mother discovers the terrible cost of alcohol in pregnancy.* Toronto: Alfred A Knopf Canada.

Capacchione, L. (2000). *The creative journal for parents: A guide to unlocking your natural parenting wisdom.* Boston: Shambhala.

Caplan, P. (1990). Making mother-blaming visible: The emperor's new clothes. *Women In Therapy, 10 (1-2),* 61-70.

Caplan, P., & Hall-McCorquodale, I. (1985). Mother blaming in major clinical journals. *American Journal of Orthopsychiatry, 55(3),* 345-353.

Chandler, G.E. (1999). A creative writing program to enhance self-esteem and self-efficacy in adolescents. *Journal of Child and Adolescent Psychiatric Nursing, 12(2),* 70-78.

Chapman, J. (1991). *Journaling for joy: Writing your way to personal growth and freedom.* California: Newcastle Publishing Co.

Chodorow, N., & Contratto, S. (1982). The fantasy of the perfect mother. In B.Thorne & M. Yalom (Eds.), *Rethinking the family* (pp. 54-75). New York: Longman.

Clandinin, J. D., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research.* San Francisco, CA: Jossey-Bass.

Cole, A. (1991). Interviewing for life history: A process of ongoing negotiation. *RUCCUS Occasional Papers, 1,* 185-207.

Colin, A. (1997). *Willie: Raising and loving a child with attention deficit disorder.* New York: Viking Penguin.

Connelly, F. M., & Clandinin, J. D. (1990). Stories of experience and narrative inquiry. *Educational Researcher, 19(5),* 2-14.

Crawford, J., Kippax, S., Onyx, J., Gault, U., & Benton, P. (Eds.). (1992). *Emotion and gender: Constructing meaning from memory.* London: Sage Publications.

Crittenden, A. (2001). *The price of motherhood: Why is the most important job in the world still the least valued.* New York: Henry Holt and Company.

Crothers, S.M. (1916). A literary clinic. *Atlantic Monthly, 118,* 291-301.

Crowe, T. K., VanLeit, B., Berghmans, K. K., & Mann, P. (1997). Role of perceptions of mothers with young children: The impact of a child's disability. *American Journal of Occupational Therapy, 51(8),* 651-661.

Crowe, T. K., VanLeit, B., & Berghmans, K. K. (2000). Mother's perceptions of child care assistance: The impact of a child's disability. *American Journal of Occupational Therapy, 54(1),* 52-58.

Cullinan, M. (1997). *Creating an adult writing group: Composing ourselves.* Unpublished master's thesis, McGill University, Montreal, Quebec, Canada.

Cutler, E. (2004). *A thorn in my pocket: Temple Grandin's mother tells the family story.* Texas: Future Horizons, Inc.

Dally, A. (1982). *Inventing motherhood. The consequences of an ideal.* London: Burnett Books.

de Beauvoir, S. (1949). *The second sex.* New York: Vintage Books.

de Marneffe, D. (2004). *Maternal desire: On children, love and the inner life.* New York: Back Bay Books, Little, Brown & Co.

Dias, P., Beer, A., Ledwell-Brown, J., Paré, A., & Pittenger, C. (1992). *Writing for ourselves / Writing for others.* Scarborough, Ontario: Nelson Canada.

Doe, J. (2003). *The story of Jane Doe.* Toronto, Ontario: Random House of Canada.

Douglas, S. J., & Michaels, M. W. (2004). *The mommy myth: The idealization of motherhood and how it has undermined women.* New York: Free Press.

Ellison, K. (2005). *The mommy brain: How motherhood makes us smarter.* New York: Basic Books, Perseus Book Group.

Ely, M., Anzul, M., Friedman, T., Garner, D., & McCormack Steinmetz, A. (1991). *Doing qualitative research: Circles within circles.* London, New York, Philadelphia: The Falmer Press.

Emig, J. (1977). Writing as a mode of learning. *College Composition and Communication, 28(2),* 122-128.

Epston, D. (1994) Extending the conversation. *Family Therapy Networker Nov/Dec*: 31-9, 62-3.

Featherstone, B. (1999). Taking mothering seriously: The implications for child protection. *Child and Family Social Work, 4,* 43-53.

Fitzpatrick, J.G. (1998). *Once upon a family: Read-aloud stories and activities that nurture healthy kids.* New York: Penguin Putnam.

Foli, J. K. (2002). *Like sound through water: A mother's journey through auditory processing disorder.* New York: Simon & Schuster.

Ford, A. (2003). *Laughing Allegra.* New York: Newmarket Press.

Fowler, M. (1993). *Maybe you know my kid: A parent's guide to identifying, understanding, and helping your child with attention deficit hyperactivity disorder.* New York: Birch Lane Press.

Freedman, J., & Combs, G. (1996). *Narrative therapy: The social construction of preferred realities.* New York: W.W. Norton & Co.

Freeman, J., Epston, D., & Lobovitz, D. (1997). *Playful approaches to serious problems: Narrative therapy with children and their families.* New York: W.W. Norton & Company, Inc.

Gage, J. T. (1986). Why write? In A. R. Petrosky & D. Bartholomae (Eds.), *The teaching of writing: Eighty-fifth yearbook of the national society for the study of education part II* (pp.8-29). Chicago, Illinois: the University of Chicago Press.

Gartner, D., & Schultz, N. M. (1990). Establishing the first stages of early reciprocal interactions between mothers and their autistic children. In J. P. Knowles & E. Cole (Eds.), *Woman defined motherhood* (pp. 159-167). New York: Haworth Press.

Gere, A. R. (1987). *Writing groups: History, theory, and implications*. Il: Southern Illinois University Press.

Gold, J. (1990). *Read for your life: Literature as a life support system*. Markham: Fitzhenry & Whiteside.

Gold, J. (2002). *The story species: Our life-literature connection.* Markham: Fitzhenry & Whiteside.

Goldberg, N. (1986). *Writing down the bones: Freeing the writer within*. Boston: Shambhala.

Government of British Columbia Ministry of Education. *Teaching students with attention-deficit/hyperactivity disorder*. Retrieved November 15, 2005, from http://www.bced.gov.bc.ca/specialed/adhd/managed.htm

Greenberg, L. S. (2002). *Emotion focused therapy.* Washington, D.C.: American Psychological Association.

Guarino, L. (1999). *Writing your authentic self.* New York: Dell Trade Paperback.

Guba, E. G., & Lincoln, Y. S. (1989). *Personal communication*. Beverly Hills, CA: Sage.

Haaken, J. (1998). *Pillar of salt: Gender, memory, and the perils of looking back.* New Brunswick, New Jersey and London: Rutgers University Press.

Hamilton, S. J. (1995). *My name's not Suzie: A life transformed by literacy*. Portsmouth: Boynton/Cook Publishers.

Haug, F., et al. (1987). *Female sexualization: A collective work of memory*. London: Verso.

Heffner, E. (1980). *Mothering.* Garden City, NY: Doubleday Anchor.

Herrington, A. (1981). Writing to learn: Writing across the disciplines. *College English, 43*, 379-87.

Hobbs, N., Perrin, A., & Ireys, S. (1986). *Chronically ill children and their families.* San Francisco: Jossey-Bass. Cited in Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children: A systems approach to childhood disability* (2nd ed., p. 90). New York: The Guilford Press.

Hochschild, A., (1989). *The second shift.* Avon Books, New York.

Hughes, C. B., & Caliandro, G. (1996). Effects of social support, stress, and level of illness on caregiving of children with AIDS. *Journal of Pediatric Nursing, 11(6),* 347-358.

Janesick, V. J. (1994). The dance of qualitative research design: Metaphor, methodolatry and meaning. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 209-219). Thousand Oaks, CA: Sage.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2,* 217- 250.

Keahey, D., & Schnitzer, D. (2003). *The madwoman in the academy: 43 women boldly take on the ivory tower.* Calgary, Alberta, Canada: University of Calgary Press.

Keen, S. (1990). *The power of stories workshop: Illuminating your life's meaning through stories.* Boulder: Sounds True Audiotapes.

Kephart, B. (1998). *A slant of sun: One child's courage.* New York: W. W. Norton & Company.

Keyes, R. (1995). *The courage to write: How writers transcend fear.* New York: Henry Holt & Co.

Kindig, E. S. (1997). *Remember the time... ?: The power & promise of family storytelling.* Downers Grove: Intervarsity Press.

Klein, K.W. (1998). *NC state psychologist studies effects of stress on working memory.* Retrieved March 20, 2000, from http://www.ncsu.edu/ncsu/univ_relations/news_services/press_releases/98_08/269.htm

Knoblauch, C. A., & Brannon, L. (1983). Writing as learning through the curriculum. *College English, 45(5),* 465–474.

Kotre, J. (1995). *White gloves: How we create ourselves through memory.* New York: Free Press.

Krueger, R. A. (1994). *Focus groups: A practical guide for applied research.* Thousand Oaks, CA: Sage Publications.

Kubler-Ross, E. (1997). *On death and dying.* New York: Simon & Schuster.

Kuhn, A. (1995). *Family secrets: Acts of memory and imagination.* London and New York: Verso.

Laborde, P. R., & Seligman, M. (1991). Counseling parents with children with disabilities. In M. Seligman (Ed.), *The family with a handicapped child* (2nd ed., pp. 337-369). Boston: Allyn & Bacon.

Larson, R. (1985). Emotional scenarios in the writing process: An examination of young writers' affective experiences. In M.Rose (Ed.), *When a Writer Can't Write: Studies in Writer's Block and Other Composing Problems* (pp.19-42). New York: Guilford Press.

Lederman, L.C. (1990). Assessing educational effectiveness: The focus group interview as a technique for data collection. *Communication Education, 38,* 117-127.

Lerner, H. (1999). *The mother dance: How children change your life.* New York: Harpercollins.

Lie, H. R., Borjeson, M. C., Lagerkvist, B., Rasmussen, F., Hagelsteen, J. H., & Lagergren, J. (1994). Children with myelomeningocele: The impact of disability on family dynamics and social conditions: A Nordic study. *Developmental Medicine and Child Neurology, 36(11),* 1000-1009.

Lustig, J. L., Ireys, H. T., Sills, E. M., & Walsh, B. B. (1996). Mental health of mothers of children with juvenile rheumatoid arthritis: Appraisal as a mediator. *Journal of Pediatric Psychology, 21(5),* 719-733.

Maguire, J. (1998). *The power of personal storytelling: Spinning tales to connect with others.* New York: Jeremy P. Tarcher/Putnam.

Manguel, A. (1996). *A history of reading.* Toronto: Alfred A. Knopf.

Marsh, J. D. B. (Ed.). (1994). *From the heart: On being the mother of a child with special needs.* Bethesda: Woodbine House.

Maurice, C. (1994). *Let me hear your voice: A family's triumph over autism.* New York: Ballantine Books.

Mauthner, N., & Doucet, A. (1998). Reflections on a voice-centered relational method. In J. Ribbens & R. Edwards (Eds.), *Feminist dilemmas in qualitative research* (pp. 119-146). Thousand Oaks, CA: Sage.

Maykut, P., & Morehouse, R. (1994). Qualitative data analysis using the constant comparative method. In *Beginning qualitative research: A Philosophical and practical guide* (pp. 126-149). London: Falmer.

McDonnell, J. T. (1991). Mothering an autistic child: Reclaiming the voice of the mother. In B.O. Daly & M.T. Reddy (Eds.), *Narrating mothers: Theorizing maternal subjectivities.* Reddy Knoxville: University of Tennessee Press. Cited in S. Ruddick (Ed.), *Maternal thinking towards a politics of peace* (p. xv). London: The Women's Press.

McGee, M., Nagel, L., Moore, M. K. (2003). A study of university classroom strategies aimed at increasing spiritual health. *College Student Journal, 37(4)*, 583-594.

McGihon, N. N. (1996). Writing as a therapeutic modality. *Journal of Psychosocial Nursing and Mental Health Services, 34(6),* 31-35.

Mickelson, J. R. (2000). *Our sons were labelled behaviour disordered: Here are the stories of our lives.* Troy, New York: Educator's International Press Inc.

Miller, J. (1996). Trick or treat?: The autobiography of the question. *English Quaterly, 27,* 3.

Miller, W. L., & Crabtree, B. F. (1994). Clinical Research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 340-352). Thousand Oaks, CA: Sage.

Mitchell, C., & Weber, S. (1999). *Reinventing ourselves as teachers: Beyond nostalgia.* London and Washington, D.C.: Falmer Press.

Morrison, T. (1996). Memory, creation, and writing. In J. McConkey (Ed.), *The Anatomy of Memory: An Anthology* (pp. 212-218). New York and Oxford: Oxford University Press. Cited in C. Mitchell & S. Weber (Eds.), *Reinventing ourselves as teachers: Beyond nostalgia* (p. 46). London and Washington, D.C.: Falmer Press.

Nakano Glenn, E. (1994). Social constructions of mothering: A thematic overview. In E. Nakano Glenn, G. Chang, & L. Rennie Forcey (Eds.), *Mothering: Ideology, experience & Agency* (pp.1-29). New York: Routledge.

Nelson, L.G. (1994). *Writing and being: Taking back our lives through the power of language.* Philadelphia: Innisfree Press, Inc.

Nylund, D. (2000). *Treating Huckleberry Finn: A new narrative approach to working with kids diagnosed with ADD/ADHD.* San Francisco: Jossey-Bass.

Odell, L. (1980). The process of writing and the process of learning. *College composition and communication, 36,* 42-50.

Ong, L. C., Afifah, I., Sofiah, A., & Lye, M.S. (1998). Parenting stress among mothers of Malaysian children with cerebral palsy: Predictors of child- and parent-related stress. *Annals of Tropical Paediatrics, 18(4),* 11-13, 301-307.

Ontario Association for Families of Children with Communication Disorders. *Getting school services to meet your child's needs.* Retrieved November 15, 2005, from http://www.oafccd.com/factshee/fact18.htm

O'Reilly Scanlon, K. (2001). *She's still on my mind: Teachers' memories, memory-work and self- study.* Montreal: McGill University.

Oxlade, R. What is Bibliotherapy? *ABAL (Association for Bibliotherapy and Applied Literature)* Retrieved August 2, 2004, from http://laurentian.ca/abal/biblio.htm.

Pardeck, J. T., & Pardeck, J. A. (1993). *Bibliotherapy: A clinical approach for helping children.* Langhorne: Gordon and Breach Science Publishers.
Parker, R. (1997). The production and purposes of maternal ambivalence. In W. Hollway & B. Featherstone (Eds.), *Mothering and ambivalence* (pp. 17-36). London: Routledge.

Parker, R. (1997). The production and purposes of maternal ambivalence. In W. Hollway and B. Featherstone (Eds.), *Mothering and ambivalence* (pp. 17-30). New York: Routledge.

Parker, R. P., & Goodkin, V. H. (1987). *The consequences of writing: Enhancing learning in the disciplines.* Upper Montclair: Boynton/Cook Publishers, Inc.

Parker West, L. (2002). *Soccer moms, welfare queens, waitress moms and super moms: Myths of motherhood in state media coverage of child care.* MARIAL Center, Emory University, MARIAL Working Paper 16.

Patterson, J. M. (1991). A family systems perspective for working with youth with disability. *Pediatrician, 18,* 129-141.

Pearson, A. (2002). *I don't know how she does it: The life of Kate Reddy, working mother.* New York: Alfred A. Knopf.

Peterson, K. E., (1999) *Stop putting it off: A handy-guide to battling procrastination.* MPA, USA: Writers Digest.

Pithers, W. D., Gray, A., Busconi, A., & Houchens, P. (1998). Caregivers of children with sexual behavior problems: Psychosocial and familial functioning. *Child Abuse and Neglect, 22(2),* 129-141.

Powell, R.A., & Single, H. M. (1996). Focus groups. *International Journal of Quality in Health Care*, 8(5), 499-504.

Price Knowles, J. (1990). Woman-defined motherhood. In J. Price Knowles and E. Cole (Eds.), *Woman-defined motherhood* (pp. 1-5). New York: Haworth Press.

Progoff, I. (1992). *At a journal workshop: Writing to access the power of the unconscious and evoke creative ability.* New York: J.P. Tarcher, Inc.

Quindlen, A. (2004, January 12). Flown away, left behind. *Newsweek.* Cited in Ellison, K. (2005). *The mommy brain: How motherhood makes us smarter (p. 5).* New York: Basic Books, Perseus Book Group.

Rainer, T. (1997). *Your life as story: Discovering the "New Autobiography" and writing memoir as literature.* New York: Penguin Putnam Inc.

Rich, A. (1977). *Of woman born. Motherhood as experience and institution.* New York: London Virago.

Rich Harris, J. (1998). *The Nurture Assumption: Why children turn out the way they do.* Touchstone. New York, NY.

Richardson, L. (1994). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pg 516-529). Thousand Oaks, CA: Sage.

Rico, G. L. (1994). The heart of the matter: language, feeling, stories, healing. In A. G. Brand, & R. L. Graves (Eds.), *Presence of mind writing and the domain beyond the cognitive* (pp. 119-214). Portsmouth, NH: Boyton/ Cook Publishers Heinemann.

Riordan, R. J., & Wilson, L. S. (1989). Bibliotherapy: Does it work? *Journal of Counseling and Development, 67(9),* 506-507.

Robson, K. S., & Moss, H. A. (1970). Patterns and determinants of maternal attachment. *Journal of Pediatrics, 77,* 976-985.

Rosenberg, H. (1988). Motherwork, stress and depression: The costs of privatized social reproduction. In B. Fox (Ed.), *Family bonds and gender division: Readings in the sociology of the family* (pp. 379-397). Toronto: Canadian Scholars Press.

Rosenblatt, L. (1968*). Literature as exploration (Rev.ed.).*New York: Nobel & Nobel Publishing Inc.

Ruddick, S. (1995). *Maternal thinking: Towards a politics of peace.* London: The Women's Press.

Ruffolo, M. C., Sugamele, M., & Taylor-Brown, S. (1994). Scapegoating of mothers: A study of mother blaming in case studies included in Core Foundation. Social Work Practice Textbooks. *Journal of Teaching in Social Work, 10(1/2).*

Schlichter, C. L., & Burke, M. (1994). Using books to nurture the social and emotional development of gifted students. *Roeper Review, 16(4),* 280-283.

Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children: A systems approach to childhood disability (2nd ed.).* New York: The Guilford Press.

Seroussi, K. (2000). *Unraveling the mystery of autism and pervasive developmental disorder: A mother's story of research and recovery.* New York: Simon & Schuster.

Shapiro Kramer, L. (1996). *Uncommon voyage: Parenting a special needs child.* New York: Faber & Faber.

Shilts, D. (1999). *Love is a start... The real challenges of raising children with emotional disorders.* Oregon: LookAgain Publishing.

Siegel, D. J. (1999). *The developing mind.* New York: The Guilford Press.

Spock, B. (1963). *Baby and child care*. New York: Pocket Books.

Stacey, P. (2003). *The boy who loved windows: Opening the heart and mind of a child threatened with autism.* Cambridge, MA: Da Capo Press.

Stallard, P., & Dickinson, F. (1994). Groups for parents of pre-school children with severe disabilities. *Child: Care, Health and Development, 20(3),* 197-207.

Stanek, L. W. (1996). *Writing your life: Putting your past on paper.* New York: Avon.

Stanley, J. D. (1999). *Reading to heal: How to use bibliotherapy to improve your life*. Boston: Element.

Stewart, M. J., Ritchie, J. A., McGrath, P., Thompson, D., & Bruce, B. (1994). Mothers of children with chronic conditions: Supportive and stressful interactions with partners and professionals regarding caregiving burdens. *Canadian Journal of Nursing Research, 26(4),* 61-82.

St-Onge, M., & Lavoie, F. (1997). The experience of caregiving among mothers of adults suffering from psychotic disorders: Factors associated with their psychological distress. *American Journal of Community Psychology, 25(1),* 73-94.

Strayhorn, J. (1988). *The competent child: An approach to psychotherapy and preventive mental health.* New York: Guilford Press.

Sullivan, T. (1995). *Special parent, special child: parents of children with disabilities share their trials, triumphs, and hard-won wisdom*. New York: J. P. Tarcher.

Swigart, J. (1991). *The myth of the bad mother: Parenting without guilt.* New York: Doubleday.

Tang, P. C., Newcomb, C., Gorden, S., and Kreider, N. (1997). Meeting the information needs of patients: Results from a patient focus group. *Proceedings of the AMIA Annual Fall Symposium,* 672-6.

Thomas, D. (1995). *Teachers' stories*. Buckingham, UK: Open University Press.

Tryssenaar, J. (1995). Interactive journals: An educational strategy to promote reflection. *American Journal of Occupational Therapy, 49(7)*, 695-702.

Van Manen, M. (1990). *Researching lived experience: human science for an action sensitive pedagogy.* London, ON: Althouse Press.

Vance, T. (1998). *Letters home: How writing can change your life.* New York: Pantheon Books.

Villani, S. L., & Ryan, J. E. (1997). *Motherhood at the crossroads: Meeting the challenge of a changing role.* New York: Insight Books.

Warner, J. (2005). *Perfect madness: Motherhood in the age of anxiety*. New York: Penguin Group.

White, M. (1991). Deconstruction and therapy. *Dulwich Center Newsletter, 3*, 21-40.

Appendix A

Writing Group Questionnaire

1. What did you like best about this session?
2. What did you like least about this session?
3. How did you feel/what did you think, about your writing this week?
4. How did you feel/what did you think, when you read your work aloud?
5. How did you feel/what did you think, when you listened to the writing/reading of others?
6. How did you feel/what did you think, while you were writing in the group?
7. a) Do you prefer writing at home, in the group, or both?

   b) Why do you prefer writing at home, in a group or both?
8. What would you like to do with the writing you've done in the past week?
9. Other comments or questions?

Appendix B

Welcome to Holland

Emily Perl Kinglsey

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this …

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. Michelangelo's David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So, you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around … and

you begin to notice that Holland was windmills … and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy … and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away … because the loss of that dream is a very, very significant loss.

But … if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things … about Holland.

Appendix C

The Project – An Invitation

Attention Mothers of "Special Children" (i.e., children with special needs)

Do you ever feel overwhelmed, anxious, upset, confused? Do you feel at times that no one understands? Do you feel like you have no time for yourself while at the same time you feel alone?

If any of these statements apply to you, you may be interested in a pilot program, a writing group for parents. This group will use narrative therapy to help you with some of the issues mentioned above, through writing for yourself, writing for others and reading the writings of those in your group. No exceptional writing skills are required, and the child may be of any age or diagnosis.

Using the principles of therapeutic writing and facilitated by a trained psychologist, the group will explore individual, self-selected topics related to parenting children with special needs. Participants will be assigned various journal writing and other exercises, and meet weekly in a supportive, non-critical session to discuss their own, and others' efforts.

The goal of the workshop is to provide an opportunity for parents to develop problem solving strategies, through therapeutic writing techniques, to deal with parenting issues of concern in their personal lives.

Participants will have the opportunity to get their point across to others or help others with their story. The project may culminate in a book entitled "Special People, Exceptional Stories."

This program is part of a Pilot project, therefore there will be no monetary commitment. There is a commitment of your time, however.

This group will take place weekly for 12 to 15 weeks, 1 ½ hours per session.

For more information please call 695-8118

Appendix D

Semi-Structured Interview – Pre-Project

1. What are your early memories of writing?
2. How have you used writing in your life, in general?

   Then more specifically:

   - To learn?
   - To remember?
   - To think?
   - To problem solve?
   - To communicate?
   - To feel?
   - Other?
3. What made you decide to join this writing group?
4. What are your expectations? Objectives? Hopes? Fears?
5. What type of writing do you enjoy reading most? Comedy? Drama? Novels? Short Stories? Self Help? Non-fiction? Biographies? Autobiographies? Comics? Magazines? Others?
6. Have you read something recently that you enjoyed? Discuss its style, content, impact on you.
7. Which aspect of 6) do you feel is most important in your critique of the writing of others?
8. What do you like to write most: poems, short stories, diary/journal, lists/notes, letters, novels, autobiography/memoirs?
9. Other comments?

Appendix E

Writing Group List of Sessions

Session One: Introduction

Session Two: Writing and/or Critiquing Poetry or Narratives

Session Three: Writing Angry Letters

Session Four: Writing to Music

Session Five: Writing with a Prompt-Object

Session Six: Writing Letters of Gratitude and/or Praise

Session Seven: Writing About a Memory Positive or Negative

Session Eight: Writing an Advocacy Letter, Message or Policy Statement

Session Nine: Writing an Advertisement of Job Description for a Mother

Session Ten: Writing using a Photograph as a Prompt

Appendix F

Informed Consent Form to Participant in Research

This is to state that I agree to participate in the research project entitled: "Writing as a Therapeutic Tool for Mothers of Children with Special Needs," conducted by Harriet Greenstone under the supervision of Dr. Claudia Mitchell, Department of Educational Studies, McGill University.

1. Purpose

I understand that goals of the present study are to use writing as a therapeutic means for mothers who have at least one child with special needs, special needs meaning any intellectual, developmental, behavioral disability or chronic medical condition.

2. Procedures

I understand that my participation will include weekly group meetings for onr hour and a half each week, and working on written activities both in the group and in between group sessions, if I so desire. I understand that the participants of the group will be recruited through advertisement and will be participating on a volunteer basis.

3. Conditions of Participation

I understand that all of the information, that is, all of my writing and any personal information about myself, will be kept in a locked filing cabinet for a period of two years, after this study is completed and that any interviews, group or individual, which will be recorded by audio tape will be destroyed as soon as they have been transcribed and the transcription will be kept in a locked filing cabinet for the period of two years after this study.

I am aware as well that my written work and that information about myself will be used in a research thesis, although my identity will be anonymous and specific details about me will be altered slightly.

I understand the purpose of the study. I understand that I am free to withdraw at any time from this study without any penalty or prejudice.

Name (please print):_____

Signature:_____

Date:_____

Appendix G

Chapter Headings

1. You don't know what it's like to be me.
2. To tell or not to tell
3. Labels - Don't judge my child by his behavior
4. My child is a person not a diagnosis
5. When your best is not enough
6. When thinking hurts
7. When joy sneaks up on you
8. Just plain anger!
9. New beginnings, new horizons
10. Where do I fit in? (Siblings' view or siblings speak out)
11. What planet is this? (first reactions, diagnosis, etc)
12. And the questions never stop
13. Feelings: No such thing as right or feelings without judgment
14. Life is a rollercoaster
15. Hanging on a cliff

Appendix H

Post-Project Questionnaire

Why did you initially join the writing group?

What objectives did you have?

Emotional
Practical
Support
Problem Solving
Other

Did you feel you accomplished any or all of your goals?

Were there any benefits/goals you achieved that you hadn't planned on or expected?

What did you enjoy overall the most?

What did you enjoy the least?

Was (were) there any particular piece(s) of your own writing that affected you in a significant way – Positive or negative? Which one(s) and how?

Was there any piece of someone else in the group's writing that affected you significantly. If yes, why?

Was/were there any discussion(s) about writing in general, or the writing done in this workshop that affected you significantly?

Overall, describe your experience in the group.

Do you feel you have changed or were overall affected after this workshop?

What changes in the program would you recommend to those organizing or participating in a group like this?