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**TELLING A DIFFERENT STORY:
IMPLICATIONS OF CONSTRUCTIVISM FOR THE COUNSELLING
OF PARENTS OF CHILDREN LABELLED WITH DISABILITIES**

by

Jay A. Goddard

B.A., The University of British Columbia, 1984

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ABSTRACT

This study explores the theoretical implications of a deconstructed view of disability to the counselling and support of children labelled with disabilities. Utilizing an open-ended focus group research design the stories of parents of children with various kinds of impairment were collected. Parents' narrative accounts of raising their children with disabilities were analysed using criteria derived from the constructivist principles of narrative therapy with particular attention to the concept of deconstruction. Three groups of parents were interviewed for a total of 15 participants. Parents were recruited using convenience and purposive sampling procedures. The majority of parents (n=12) were the biological parents of children with various impairments, were from middle income level families (n=13), and European Canadian ethnic backgrounds (n=13). All of the parents in the study had at least a grade 12 education and the majority (n=12) some college or university education.

The study hypothesized that parents' narratives would deconstruct dominant discourses on disability and being the parent of a child with disabilities. It asked questions about the ways parents deconstructed dominant discourses, whether parents' narratives identified assumptions, what kinds of issues were relevant for counsellors and whether constructivist theoretical principles are useful in the counselling of parents of children labelled with disabilities

Utilizing a grounded hermetic analysis, results yielded 10 themes: horrible pictures, parent essentializations, affective issues, deconstructions of normal parenting, comparisons, meeting a child needs, bureaucracy, larger discourses, labelling and diagnosis, and generalized views of the experience. Results are presented within four thematic categories: stories about other people's assumptions, stories about dealing with difference, stories about professionals and finally stories about disability.

Results provide examples of how parents' stories fit within a deconstructive framework and suggest that these parents are engaged in a process of active deconstruction and reconstruction of their experiences. This process is concerned with assumptions by other people about what their experience is "supposed to be like" as well as stereotypes about disability in general. These results suggest specific recommendations for counsellors working with the parents of children with disability as well as recommendations for policy and the training and education of professionals working in disability-related fields.

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CHAPTER 1

INTRODUCTION

A research and professional literature on the counselling and support of parents of children labelled with disabilities exists within the fields of psychology, social work and education. This literature defines parents' needs for counselling and support, describes characteristics of families where children have disabilities, and presents helping strategies for working with parents and families where disability is an issue.

Within the field of disability-related studies there is also an increasing interest in examining assumptions about the social construction of disability. Individuals who have been assigned a disability label, as well as their advocates, are the primary contributors to this emerging perspective. Many of their positions challenge long standing assumptions about the "reality" of having a disability. They argue that people labelled disabled have faced oppression and prejudice in a society which has created reified notions of normal and abnormal. Such notions are highly evaluative and subjective, and have been internalized by people with and without disabilities.

A critical study of the social construct of disability, which is just beginning to be explored within the professional literature, has implications for families and the people who help them. The following study describes the social construct of disability from a critical perspective and explores its implications for the counselling and support of parents and families of children with disabilities. The present study also explores the possibility that constructivist counselling theories offer a useful framework for working with this population and can resolve some of the theoretical challenges presented by evolving critical discourses on disability. There are different stories being told about being different, and increasingly, counselling with this population is seen to be about helping parents create their own version of a story which is positive and helpful rather than tragic

and hopeless.

Statement of the Problem

Finkelstien's (1993) comment that, "Those who enact helping interventions need to recognize that the changing meaning of disability provides a new context for the construction of services with disabled people on a quite different, dynamic understanding of disability" (p. 15) guided the conception of this study. Similarly, Ferguson and Ferguson (1995) point out the importance of individual stories when they state: "So let us tell our stories: recognize them as legitimate. Listen to the stories of others; appreciate them as additions, not as contradictions. And most important, proclaim the value of those whose stories so often go untold" (p. 119). Both of these perspectives represent contrasts to tragic stories about being the parent of a child with disabilities. Tragic stories are not based on a dynamic definition of disability and come from a legacy of the single story. Whereas individuals with disabilities have held up the experience of being disabled to a critical analysis, the experience of being the parent of a child with disabilities has received much less critical examination.

In this study, I examine the constructed nature of the meaning of disability, explore the ways in which counsellors and other professionals help families of children with disabilities based on particular assumptions about being disabled and about being the parent of a disabled child, and I explain why it is important to recognize that there are many stories about being different and being the parent of someone who is seen to be different. This study is primarily a theoretical and exploratory work written from a constructivist theoretical perspective.

The Definition Of Disability Used in This Study

This study defines disability in broad terms and is inclusive of physical, cognitive, sensory and psychiatric impairments. This approach to defining disability represents a cross-disability

perspective (Taylor, 1996; Shapiro, 1993). While there are significant differences in experience between individuals with different impairments, the use of a cross-disability definition is to address those issues which are common to all disabilities. A cross-disability definition recognizes that, regardless of specific functional difference, people with impairments face discrimination and are denied accommodation within mainstream society. The definition of disability in this study is about particular social constructions of difference in functional ability. Disability is a construction that defines various differences in people's abilities to see, hear, think, ambulate, move, feel, speak or learn.

This definition is congruent with the definition of disability articulated by the World Health Organization (1980) which makes the distinction between impairment (the actual condition of functional difference) and disability and handicap (various social impositions of disadvantage on people with impairments). Disability, according to this definition, is a relativistic concept which recognizes the "interaction between societal conditions or expectations and the abilities of the individual" (U.N. Document, 1993 p.6). This definition contrasts traditional medical or deficit models of disability which see disabilities, handicaps and impairments as problems of individual adaptation. Lenny (1993) extends the use of this definition by stating that disability is a problem not of the individual but of the disabling society.

Definition of Critical Constructivism

Constructivism, according to Gallant (1993), represents an epistemological position based on the central concept that "'reality' is constructed by the observer and is not an external entity entirely separate from the observer" (pg. 119). Marshall (1996) and Prawatt (1996) distinguish several versions of constructivism in the field of psychology including cognitive and socio-cultural approaches that stem from a variety of sources. Olssen (1996) critiques the idea that all reality is

constructed, particularly as applied to the process of knowledge acquisition. He does, however, point to the social constructivism of Vygotsky and Foucault as useful social theses in the fields of psychiatry and psychotherapy:

In Foucault's sense, constructivism is achieved by historically evolved discursive systems (e.g. psychiatry) which 'construct' the reality they posit in the sense that the ontological status of objects of concern (e.g. states of mind) cannot be divorced from the conceptual matrix through which they are apprehended. While such claims constitute a strong constructivist programme, they are more relevant as a social thesis and not as a claim about individual learning (p. 291).

This study accepts the existence of the underlying conditions of functional difference or impairment. Spinal cords, optic nerves and neural pathways are things in the real world that sometimes function differently in different individuals. How those differences are perceived, adapted to and socially constituted is the chief concern of this study and is congruent with Olssen's description of social constructivist theories as social theses. Traditionally, disability has been understood from the conceptual matrix of people without disabilities. People living with impairments do not necessarily share the ontological status (meaning) that they are disabled. This version of constructivism is also consistent with a humanist theoretical orientation which sees the use of constructivism in pragmatic terms as a tool for the promotion of social equality (Kiel, 1995). Disability, in this sense, has been historically constructed by individuals in positions of privilege as a means of validating their own "normality" and, by extension, superior status as humans.

In the field of counselling, narrative therapy represents a critical social constructivist position, derived from the philosophical work of Foucault. Narrative therapists propose that "it is

the meaning that (family) members attribute to events that determines their behavior” (White & Epston, 1990, p.3). A theoretical notion underpinning narrative therapy is that meaning is shaped by larger and often subjugating cultural discourses. (Zimmerman & Dickerson, 1996). The concept of a subjugating cultural discourse is derived from the work of Foucault (1954) and refers specifically to a set of culturally derived values about reality and what is considered normal.

Critical Definitions of Disability and Parenting

Critical constructivist definitions of disability emerged in the 1980s in the work of researchers and theorists, primarily in Britain and Europe (Chappell, 1992; Ward & Flynn, 1994; Shakespeare, 1993). One idea proposed in these theories is that disability is a construction of material conditions in society. “Disability comes not from bodily impairment, but from the social and economic restrictions imposed on the individual which disable him/her” (Chappell, 1992). Shakespeare distinguishes American from European disability movements by the former’s concern for “individual rights and competitive values” versus the latter’s emphasis “on changing the system that produces disability”(p. 250).

Framing the challenge of counselling parents of children labelled with disabilities from a critical constructivist perspective is both useful and relevant because this position emphasizes both systemic and ontological issues. Furthermore, this perspective is already reflected in the stories parents tell about their experiences in raising a child with disabilities. The meaning of disability, Finkelstein (1993) notes, is dynamic and multidimensional. Disability, for many, no longer equates with tragedy, dependence and helplessness. New meanings include the notion that a disability is socially created and impairments are only construed as disabilities within a particular social, historical or material context (Tomlinson, 1995; Gelb & Mizokawa, 1986). The tragedy of living with an impairment is in society’s lack of acceptance of individuals with certain kinds of physical

or intellectual differences. Social systems which emphasize standardization and a static conception of normality disable individuals who do not fit within those standards or norms.

At the same time, the persistence of subjugating cultural discourses, or what narrative therapists term "dominant stories" (Parry & Doan, 1994), continues to have considerable influence in the lives of individuals with disabilities and their parents. The tragedy of being significantly impaired continues to be taken for granted as true. The current attention to the conviction of Robert Latimer for the murder of his daughter, Tracey, is a case in point. Tracey was an 11 year old girl with cerebral palsy whose father placed her in a closed garage in a running vehicle where she died of carbon monoxide poisoning. Robert Latimer claimed he acted to end his daughter's suffering (Sobsey, 1991). Some of the public reaction to the Latimer trial, while mixed, has been sympathetic to Mr. Latimer and outraged at the justice system that he received such a harsh penalty. In many people's minds it wasn't a murder; it was an act of mercy. According to the Roeher Institute (1996), "over 26,500 people signed a petition calling for a reduction of his sentence of life imprisonment" (p.112). The idea of death as release for people with significant physical or mental impairments is part of a much older story, yet even in the face of emergent conceptualizations of disability, it continues to be told.

The Latimer case is presented as a demonstration of the power of particular perspectives, rather than to argue the ethics of euthanasia or to assert that any form of counselling, by itself, will prevent such occurrences in the future. White (1991) refers to the pervasiveness of the construction of problems around dominant subjugating discourses. They are difficult to escape and supported by language practises (i.e., deficit models of impairment) and institutions (i.e., medicine, social welfare). The social discourse on euthanasia is a deadly serious one, but it is also embedded in the wider context of the nature of the relationship between parents and children with

disabilities and whether a society values each of its members. Some interpretations of the Latimer case, however, take for granted Tracey's "deficient" physical and mental status and see his actions as a compassionate attempt to release Tracey from her "suffering."

There exists a growing body of literature by researchers who are themselves parents of children with disabilities (Turnbull, 1988; Ferguson & Ferguson, 1995; Sobsey, 1991; 1995). While not denying the need for and value of counselling, these authors point repeatedly to professionals and professional practises that rely on stereotypes of children with disabilities and their parents. Sobsey (1995), in a news group posting to other parents of children with disabilities provides an example: "Things like telling a parent that people feel sorry from them, overemphasizing stress, etc. do not support parents' relationships with their children" (p.1).

From a constructivist perspective, the problem becomes one of whose stories are being told. Are they the parents' own stories, or are they dominated by assumptions of individuals in positions of power who have little real understanding of what it means to be the parent of a child with disability and little day-to-day experience with disability? The belief that the experiences of parents of children with disabilities are negative has only recently been challenged (Hanline, 1991). This parallels the recent challenging of the tragic construction of disability. The evaluative assumptions behind constructions of disability have been taken for granted for many years (Söder, 1993; Hahn, 1988). Within the context of emergent research in this area, these ideas are consistent with Glidden's (1993) opposition to the view "that a family with a child who has a disability is (seen to be) a family with a disability" (p. 482).

The Case for Constructivist Approaches to Counselling

There is an ongoing struggle of individuals with disabilities to overcome centuries of social oppression and exclusion, including oppression and exclusion from their own families.

Considering the depth of social exclusion in the past, the more positive current social context with respect to people with disabilities is remarkable. Like other social movements, however, it is far from complete. The most ardent opposition at the Latimer trial was that of various disabled self-advocacy groups. Their singular purpose was to ensure that the Canadian courts did not justify active euthanasia as a solution to the "problem" of disability. Despite efforts to change the social construction of disability, people with disabilities still face questions of the ultimate value of their lives.

The current study seeks to inform counsellors and other persons providing support to the parents of children with disabilities on emergent issues in both counselling and the field of disability studies. There are increasing expectations for parents of children with disabilities to accept their children for who they are rather than to focus on what they cannot do (Turnbull, 1988; Ferguson & Ferguson, 1995). A significant body of work shows that individualized parent or family-centred support, which builds on parental strengths, has beneficial effects for all family members including children with disabilities (Dunst, Trivette & Deal, 1988; 1994; Trivette, Dunst, Boyd & Hamby, 1995).

Lobbying efforts in both the United States and Canada by individuals with disabilities and their families have brought about significant legislative attempts to redress the traditional disadvantages of people with disabilities. This includes guarantees of access to employment and education, suitable housing and reasonable medical expenses, as well as protection from discrimination on the basis of disability. In the U.S., recent amendments to the Individuals with Disabilities Act (IDEA) pay particular attention to the support needs of parents of children with disabilities. In a recent study of parents, however, Apler, Schloss & Schloss (1995) cite an example of a situation where more than 50% of parents interviewed turned to litigation to meet

their needs for services. This suggests that despite the efforts of governments, not all needs are being met. Attention to the counselling needs of parents is significant in this regard. Parents of children with disabilities must navigate a service system which is threatened by diminishing resources and is increasingly under pressure to adapt to ideological debates within the community of people with disabilities. This suggests that parents of children with disabilities need to possess skills for self-advocacy and that they not be mired in the "problem saturated" narrative of tragedy and sorrow. Constructivist approaches to counselling, in particular, are seen to address both psychological as well as sociological issues.

My Interest and Bias

My interest in this area of research is rooted in my professional frustration as a college special education teacher with the barriers imposed on students with disabilities because of limiting pathological definitions of what it means to have a disability. Increasingly, I have come to see students' desires for inclusion and empowerment as legitimate attempts to assert their rights to personhood in a service system which seems to be designed to exclude and stigmatize them. In the last few years, increasing numbers of students who have been integrated in mainstream education classes have come to the college program I teach. Their expectations and frustrations are often remarkably different from older students with disabilities, many of whom remained segregated throughout their educational careers and some of whom have spent time in institutions. Younger students appear to have more of a sense of themselves, are much less dependent and are much less tolerant of being excluded and devalued. There has been a shift in consciousness and self-definiton.

I also increasingly encounter parents of young adults labelled with disabilities who are less stigmatized about their child being labelled with disabilities and more ready to help their children

to achieve specific goals. While I deal with some frustrating exceptions to these cases, I have developed the view that there is a new generation of parents who are better informed and more accepting of their children's differences. These parents appear to have reconstructed a reality in relation to their child's impairments which is based on a different view of themselves and of disability. To be sure, they are more demanding of professionals and social institutions, but I have found it makes communication much easier and ultimately creates a much better educational context than when parents present stories of stigma and denial. Their children seem to do better and present many fewer secondary issues.

At the same time, I continue to be frustrated by parents who view impairment negatively and either have few expectations of their children or expect me to fix their children's problems. In such cases, the student's acceptance of his or her own differences is often greater than the parents'. Problems arise because children cannot meet the expectation that they can be made normal. In other instances, parents denigrate the possibility that their children can be economically productive and put severe limits on a child's independence. Because of issues of confidentiality, I cannot describe specific instances. When I do encounter these views, however, there is often considerable conflict and it seems that neither parents nor children benefit.

I mention these instances as a way of elaborating my own bias as a researcher. I do not wish to blame or denigrate "bad" parents. Parents are doing what they believe is best for their children and are coping with their own issues as best they can. I see their actions as derived from a discourse on disability which is based on the stigma and tragedy of disability. Other parents, as mentioned earlier, have different stories based on different and sometimes more empowering interpretations of disability and impairment. This is not a study about good parents and bad parents; it is, rather, a study about different kinds of stories. My goal is to suggest that by

understanding positive and unique outcomes, counsellors will devise counselling strategies that foster enhanced self esteem for both individuals with disabilities and their parents.

Purpose of the Study

Past counselling and support practices can be said to contribute to the “problem saturated narrative” about parenting and disability (Beresford, 1994). A theoretical redefinition of counselling for parents is needed. Counselling ought to empower parents based on the dialogue that they articulate, rather than reflecting the assumptions of practitioners about what they imagine it is like to have a child with disabilities. This perspective also needs to include attention to unexamined assumptions about disability in general. I hope to demonstrate that constructivist counselling practise provides a useful theoretical framework for working with the parents of children with disabilities. To paraphrase a well known saying from constructivist counselling practise: the problem is not the problem but what you are doing about it is the problem (Watzlawick, Weakland & Fisch, 1974). What counsellors have been doing about the problem for many years is sympathetic but also possibly patronizing and stigmatizing. What they may need to be doing is to help clients re-contextualize problems and to make sense of the way problems are “constructed” around issues of disability.

The current study frames the counselling of parents of children with disabilities within a constructivist theoretical framework as defined by the narrative therapy approach. My purposes are two-fold. First, I will examine the narratives of parents of children with disabilities using their own voices in order to deconstruct notions about disability and being the parent of a child labelled with disabilities as told in their own voices. Secondly, I will explore the theoretical concept of deconstruction, as defined within narrative therapy with parents of children labelled with disabilities. If it is the case that parents of children with disabilities have been stereotyped and that

issues have been reduced to an “essentialized” set of common factors which do not reflect the individuality of parents nor the wide variety of possibilities in adjusting to issues of disability within a family, then it is important to deconstruct existing theories about parental response and adaptation in order to establish new approaches to counselling that acknowledge diversity.

CHAPTER 2

REVIEW OF THE LITERATURE

The following review of the literature summarizes previous research and theory on disability and counselling. In addition, it elaborates historical and contextual issues and uses a deconstructive analysis to locate contradictions and theoretical problems. In the review, I begin with a discussion of the paradigm shift from modernist to postmodern epistemology and provide a further elaboration of constructivist counselling and the concept of deconstruction. I proceed to frame the issue of parent counselling as a set of stories. Using the language of narrative therapy, these stories include: "old stories" about parents and disability with particular attention to the idea of "chronic sorrow," new and bigger stories about the counselling needs of parents, and provocative stories from the perspective of people with disabilities about parents. A hypothesis is offered based on key concepts from this review.

Paradigm Shifts

There are contradictions in the existing literature on the counselling and support of parents of children with disabilities with regard to attempts to reduce the issues of parenting a child with a disability to a set of measurable constructs (Glidden, 1993; Hornby, 1994). Historically, there are also a number of assumptions which affect how this diverse and changing population has been studied, what kinds of results are presented as legitimate knowledge and how practitioners are educated to help parents deal with issues of having a child with disabilities. When Sobsey (1995) refers to sympathy and an over-emphasis on stress, he is also referring to a body of work which has informed the training of professionals and which is based on assumptions about parental adaptation to disability and about disability itself. Many of these assumptions are negative - they

tell sad stories - and have only very recently begun to be countered by stories which are more hopeful, more empowering and more positive (Lenny, 1993; Turnbull, 1988).

The paradigm shift in the social construction of disability reflects a shift of perspective in the wider discourse about human diversity. Parry and Doan (1994) describe this as the shift from a modernist to a postmodern context of inquiry. The modernist context is informed by the certainty of science and based on the notion that reality is knowable in a singular form. In contrast, the authors describe the postmodern context as "a growing realization that no single story sums up the meaning of life...that no story or theory is sufficient to correspond fully to its subject matter" (p. 10). There is an epistemological shift from the certainty of knowing the way the world works to the uncertainty of a position which states there are many ways of knowing the world and all of them are the best attempts to construct reality based on one's experience in the world. One explanation for the difficulty science has had in identifying simple causal relationships is that multiple variables mutually interact within naturalistic contexts. For example, in her review of empirical research in the area of coping resources in families where children have disabilities, Glidden (1993) points out that because many variables are inter-correlated, researchers have failed to find relationships between the same variables in replication studies. While some researchers would contend that this points to the need for more rigorous science, researchers working within the postmodern context of enquiry point to something different.

From a postmodern perspective, science is a way of telling stories about the world that is very useful for the development of technologies but not always as useful for describing the complex interactions of human beings. According to this position, no matter how precise the instrument of measurement or carefully controlled the study, social scientists are necessarily influenced by their own assumptions and values. There are contradictions presented by exceptions

to the rule. Often the dynamic and temporal aspects of the social and historical context in which data are gathered prove most troublesome of all. This context changes over time - what might be a reflection of social reality today will be seen differently ten or twenty years from now (Ary, Jacobs & Razavieh, 1990).

Consider, for example, that at one time homosexuality was thought by a significant portion of the scientific community to be pathological and was included in the Diagnostic and Statistical Manual of Mental Disorders (DSM). It has since been removed and is no longer considered pathological nor deviant, but is instead seen more as a reflection of the natural range of human sexual experience (Coles, 1982). In the intervening time, between its inclusion and its removal, the social context changed. The gay rights movement contributed to and changed the way in which homosexuality was conceptualized. Sexuality, as a subject of academic study and scientific research, has also changed. It is questionable today, for instance, to conduct research which seeks a "cure" for homosexuality. The concept of "cure" is criticized for implying pathology when no pathology indeed exists. With the exception of some conservative religious positions, same-sex variations in human sexuality are no longer considered deviant. This example is somewhat oversimplified, but demonstrates how socially constructed phenomena change over time and with respect to the inclusion of the views of those who have been labelled deviant.

Constructivists refer to the process by which accepted truths are challenged and redefined as "deconstruction." Deconstruction is an attempt to identify contradictions and taken-for-granted assumptions about accepted versions of reality (White, 1991). The gay rights movement has deconstructed homosexuality. Feminist critique can be viewed as a deconstruction of traditional views on gender difference. The Civil Rights movement has deconstructed the social construction of race. Similarly, the disabled rights movement deconstructs the idea of disability.

Deconstruction, as a theoretical method of inquiry, involves challenging what are seen as scientific rationalizations of cultural values. An example of this is the re-examination of the origins and assumptions underlying intelligence quotient (IQ) testing. At the beginning of the century, particularly in North America, IQ testing was a culturally biased and deliberate attempt to separate "inferior" and "superior" classifications of people based on their race, gender and class (Gould, 1981; Radford, 1994). Gelb (1995) points out that what constituted low intelligence went even further than this and included things like a strong preference for the color purple and whether or not an individual engaged in masturbation. According to Rioux (1994), early research into the testing of intelligence was presented as sophisticated science when, in essence, it was the mathematical manipulation of test scores designed to validate existing ethnic, racial and class divisions as legitimate and biologically determined. North American society, at the time, was deeply divided ethnically and racially, and with regard to social class and gender. Those in positions of power and privilege (White Anglo-Saxon men) maintained a certain cultural aesthetic which valued progress, orderly behavior and a well defined hierarchy. Testing IQ was a means of maintaining the status quo.

Some of the intelligence tests developed by early psychologists are still in use today with little alteration of their original forms. The same theoretical principles which underpinned the development of IQ tests also persist. Gould (1981) points out that the science of psychometrics is trying to measure a multidimensional construct, impacted by numerous complex variables which may never be entirely understood. He also points out that intelligence is not a "thing." This set of constructs purported to measure intelligence, in fact, is really merely a score on a test, taken under particular conditions and based on culturally derived assumptions about what is correct or incorrect. Despite this criticism, millions of people who score below an arbitrary point come to be

defined by another social construction called mental retardation. It is an easy solution and masks important questions about why people who do not do well on such tests are not accepted by the larger society. In addition, the score creates a totalizing social role. I had a former client whose appraisal of being labelled mentally handicapped was summed up succinctly when he said, "We are the stupid people, la la la."

The constructivist orientation in this study questions the limits of positivist epistemology in relation to disability. The intent of this study is not, however, to dismiss or denigrate quantitative inquiry. I review both quantitative and qualitative studies of parent counselling; both traditions of research present useful information for elaborating an understanding of the research problem. In addition, I also define issues of historical and cultural context and locate contradictions to elaborate ontological (meaning-related) issues central to the recent discourse of disabled activists and critical researchers in the field of disability studies.

As an example of a contradiction in studies on the counselling needs of parents of children with disabilities, consider the following two examples of studies published the same year.

Because the belief that all parents progress through the same predetermined stages as they adapt to having a child with disabilities is now questioned, the individuality of all family members must be recognized and respected. Each parent responds in his or her unique way to having a child with a disability, and those responses must be recognized as positive...and must be respected as a reaction unique to a particular parent (not as part of a stereotypic process of adaptation) (Hanline, 1991, p. 56).

Hanline's position reflects the concerns in the present study. The following quote is informed by a different set of assumptions which are noticeably contradictory.

It has been widely recognized that parents, after learning of a child's disability or serious illness, experience a pattern of feelings and responding similar to that exhibited by other parents in that situation. Using the knowledge of stages and typical reactions, the well trained counsellor can often provide valuable support to the family during this crisis situation" (Ziolko, 1991 p. 33).

The contrast between these quotes helps to define the research problem this study seeks to address. Hanline emphasizes the individuality of parents, whereas Ziolko suggests a common pattern. Hanline speaks of unique reactions and positive responses, while Ziolko refers to a crisis situation. Hanline suggests that counsellors take an open-minded stance free of judgment, while Ziolko stresses the importance of counsellor competence and the need for specialized knowledge of stage theories. What is important to note here is that there are different sets of underlying assumptions in these two positions. Ziolko implicitly implies a certain mystique around the practise of counselling parents of children with disabilities in asserting in the same article that counsellors need to approach the task with "awe and caution" (p. 31).

It would be simplistic and misleading to say which position is correct. Ziolko's position is grounded in the fact that, for many parents, having a child with disabilities is indeed a troubling and difficult experience. Her position is problematic because it doesn't account for variations informed by different sets of assumptions about disability and parenting. Hanline, while attempting to address this issue of individuality of parents, perhaps does not stress that sometimes those reactions are very negative, leading to abusive and dysfunctional situations. Robert Latimer's response to his disabled child, from the perspective of people living with disabilities, could hardly be called positive.

These examples provide two different versions of the reality of parents and children with

disabilities. There are others which are explored later in this review. From a postmodern perspective, there is no longer just one way to view the issue of counselling parents of children labelled with disabilities. Before proceeding to a description of these varied realities, the principles of constructivism and deconstruction are further elaborated.

An Elaboration of Constructivism and Deconstruction

Within the social sciences, constructivism is a theoretical and philosophical principle derived from the central tenet that "reality" is constructed rather than being an objective and knowable "truth." Constructivists maintain that in the process of trying to understand the world, particularly the multidimensional nature of human social interaction, it is impossible to separate the observation of phenomena from the observer. In other words, the way the social scientist constructs the world and the meaning that he or she attaches to events, inevitably affects the outcome of those observations as well as what he or she selects to attend to in the first place (Becvar & Becvar, 1993). Constructivists emphasize the importance of paying attention to historical, ideological, sociological and cultural context in the production of knowledge. They critique what is presented as factual information about the world. Skrtic (1995) described constructivism as a criticism of the "functionalist paradigm" where there is an assumption of a "single social reality to which humans react mechanistically" and in which "the current arrangement of society is assumed to be functional and thus indispensable, if not inherently correct" (p.67).

Positivism maintains that reality is ultimately knowable given enough weight of evidence and the continual refinement of tools for measuring real phenomena. While constructivism contrasts with positivism, it is an oversimplification to state these two viewpoints are diametrically opposed. Modern positivist research is increasingly called upon to present the limits of its inquiry;

to emphasize that logico-empirical evidence is, at best, a guess. This is particularly so within the social sciences, where there are simply too many variables for any study to be conclusive. Constructivist inquiry, conversely, is seen to create an uncertain and ambiguous view of reality. Critics of constructivism point out that widely shared meaning is indeed a reality, and that without it a great deal of important human activity would be impossible (Olssen, 1995).

In the field of counselling, constructivism relates to both studies of helping strategies as well as to the practise of counselling itself. Constructivist researchers in counselling question theories of helping which reduce processes of healing and personal growth to a set of patterns or models. This questioning does not involve a rejection of traditional approaches to psychotherapy, but points to the need to put all models in perspective and to recognize them as a particular way of constructing the counselling process. Constructivist counselling theorists contend that various helping processes need to be seen in relation to their historical and cultural context and to include attention to the particular background of both the client and the counsellor, the setting in which counselling takes place and the wider social and cultural issues which play a part in the problems clients present. According to Peavy (1993), "It cannot be assumed that professional skill and knowledge fit every client case, nor can it be assumed that there is one right solution to each problem" (p. 32).

Modernist approaches to psychotherapy, in contrast, posit the human psyche as existing as a discrete entity with measurable parameters. Psychoanalytical and behaviourist traditions, in particular, create conditions or categories of pathology or dysfunction which can be treated by an expert trained in specific therapeutic techniques (Corey, 1991).

In contrast to modernist approaches, narrative therapy (White & Epston, 1990; Parry & Doan 1994; Zimmerman & Dickerson, 1996) represents one approach to constructivist

counselling. Narrative therapists define counselling as a process of discussion or conversation where the important metaphor is not the scientific model of the pathological individual in need of treatment but is a model of the influence of a problem narrative in the lives of those experiencing it. In psychodynamic theories, the problem is seen to be within the person and remains there throughout the course of therapy. The disease metaphor suggests problems can be removed, treated and adjusted, or, in psycho-analytical terms, that the psyche (ego, id and superego) can be reintegrated. In narrative therapy problems, are conceptualized as entities unto themselves, in a process White (1991) terms the "externalization" of the problem (p. 39). White speaks about the life of the problem or the influence of the problem rather than having problems or treating individuals for their problems. The metaphors of narrative therapy are literary rather than medical. Narrative therapists listen to people's stories and assist them in re-authoring their lives. Zimmerman and Dickerson (1996) describe narrative therapy as a way of talking about problems, or an attitude about the helping process, rather than as strictly a set of cognitive techniques.

Deconstruction in Therapy

The counselling of parents where children have disabilities is a counselling problem relevant to constructivist theory and narrative therapy. Disability, although characterized by specific functional differences or limitations, also represents a narrative about living with difference. This different way of conceptualizing the issue of disability and its relationship to parents contrasts with a view of disability as a "bad thing" that no rational parent would want. Certain narratives speak of mourning the loss of the ideal child, a burden to bear, or a tragic and unfortunate situation (Olshanksy, 1962; Ziolk, 1991). While narrative therapy does not discount those experiences, it tries to locate them as one story among many, including those stories where disability is not or has ceased to be a problem.

One of the ways in which parents move from one story to another is through the process of deconstruction. White (1991) describes deconstruction as an attempt to uncover "procedures that subvert taken for granted realities and practises: those so-called truths that are split off from the conditions and the context of their production; those disembodied ways of speaking that hide their biases and prejudices; and those familiar practises of self and relationship that are subjugating of people's lives" (p. 34). In other words, deconstruction, as employed in therapy, identifies and foregrounds those parts of people's stories which might be creating contradiction for them because they make decisions based on a story about the way they are supposed to act under certain conditions. Assumptions are challenged and clients come to see they have power over their problems and that they are able to vocalize and eventually to conceptualize a different (reconstructed) narrative theme. Deconstruction of problems can take many forms and can be applied to many types of problems. For example, Hart (1995) reviews numerous applications of White's ideas to specific problems, including case studies of families where children have been labelled with some form of disability.

Narratives about disability and about being the parent of a child with disabilities have historical dimensions. A number of stories have been told throughout human history about the way in which people with impairments and their parents are supposed to live. The next section of the literature review provides an overview of these "old stories," with attention to the historical evolution of subjugating discourses about being the parent of a child with disabilities.

Old Stories About Parents and Children with Disabilities

A full analysis of the history of being the parent of a child with disabilities is beyond the scope of the current study. The following section briefly describes concepts from a number of historical analyses which review the western historical construction of disability. The section is

organized according to Stockholder's (1994) historical taxonomy of disability, encompassing the following periods: "the archaic or classical; the medieval; the Enlightenment and; the modern" (p.161). The purpose of this section is to trace the historical roots of taken for granted realities and cultural practises as they relate to issues of being the parent of a child with disabilities.

Pre 20th Century Stories About Disability

During the classical period, people with disabilities were seen to be "outside the realm of freedom" (Stockholder, 1994 p.162). These notions reflected Plato's (n.d.) conception of human value (gold, silver and brass or iron). Women, craftsmen and slaves, and the practical and bodily tasks they performed, were seen to be inferior to or less virtuous than the intellectual and political pursuits of free men. Under this broad conception of society, people with visible impairments were considered non-human and an affront to civilized sensibilities. Infants with visible deformities were left to die at birth. Other individuals with impairments were employed to entertain as oddities and freaks.

Many individuals who would be seen to be intellectually disabled by today's standards would not have been seen as disabled in earlier times since the need for widespread literacy was not as great (Nibert, 1995). Similarly, the conceptualizations of "defect" probably did not include certain conditions of impairment which only exist today as the result of medical interventions. It is assumed therefore, that the population of people with disabilities represented a somewhat different set of impairments than is known today. These conditions remained a feature of society up to the time of the industrial revolution (Nibert, 1995).

Stockholder (1994) described the medieval period as a period when there was a dual mythological view of physical and mental impairment - the sacred and profane. Impaired individuals, during this period, provided a justification of Christian charity. People who cared for

the sick, the simple-minded and the injured were doing God's work. At the same time, individuals with certain types of disabilities (people with epilepsy or mental illnesses) were associated with demonic possession and evil. Another kind of duality existed in medieval conceptions of the fool who was simple, yet had a special wisdom (e.g., the fool in King Lear). Nibert (1995) speculates that the court jesters or fools attached to royal courts and wealthy households would today be considered intellectually impaired (Nibert, 1995).

The Enlightenment period shifted emphasis on the definition of impairment from mythological to rational or materialist conceptions. The growing interest in science brought with it a schema for classifying various forms of impairment (Stockholder, 1994). Enlightenment thinking also suggested the first formal attempts to both segregate and rehabilitate individuals considered abnormal (Roehrer Institute, 1996). Economically, as people were thrown off agricultural land and labour shifted to the factory economy, people with disabilities who had been cared for or employed at home or in monasteries had no place in mainstream society (Nibert, 1995). Institutional placement of 'defective' children was both a solution to issues of surplus population and an attempt to provide "cures" so that individuals with certain disabilities could be reintegrated into the emergent capitalist society (Rioux, 1994).

Toward the end of the nineteenth century, it became apparent to the scientific and academic community that "cures" for certain kinds of impairments were not forthcoming. In place of early rehabilitative conceptualizations of impairment, Social Darwinism came to the fore. Briefly, Social Darwinist theories misrepresented biological ideas about the survival of the fittest as a justification for, among other things, the subjugation of people with disabilities. People with impairments were seen to be socially inferior because they were biologically inferior. Such thinking grew into the notion that they represented a menace to social progress which continued

to influence conceptualizations of people with disabilities well into the modern period (Roehrer Institute, 1996).

Modern Stories About Parents and Disability

At the turn of the century, the practise of segregating people labelled with disabilities in large institutions was well established (Nibert, 1995). Institutional segregation was tied to the notion that individuals with significant physical, emotional or apparent intellectual impairment had little economic value in an industrial society which stressed conformity and standardization. This separation can also be linked to aesthetic ideals which favoured attractive, able-bodied, and apparently intelligent individuals. Hahn (1988) points out that, even today, "aesthetic anxiety" continues to play a significant part in the discrimination against individuals with disabilities. In the early part of this century, however, the rejection of individuals with disabilities was seldom questioned as discriminatory. The scientific community rationalized this social denigration and separation as the inevitable outcome of both biological and social evolution. Eugenic and degenerationist theories, according to several authors (Gelb, 1995; Nibert, 1995; Gould, 1981), were based on hierarchical notions of human inferiority and superiority, as well as the tacit racist and moralistic belief that science should play a role in perfecting the human species. Such thinking led to the institutionalization of individuals with various disabilities, as well as their sterilization without consent. In Nazi Germany, it led to medical experimentation and active euthanasia (Wolfensberger, 1981).

Parents faced with the birth or diagnosis of a child with an impairment had few choices within this kind of social context. There was a stigma attached to siring or giving birth to a "defective" child and probably, given the pervasiveness of eugenic thinking ("bad blood"), a great deal of self-recrimination and guilt. Counselling often took the form of helping parents make

decisions about institutionalization and later on helping them to “forget” about the child or reassuring them that they had made the right choice. This meant emphasizing that their child was better off in the care of trained professionals or with “their own kind.” In the extreme, some scientists openly advocated euthanasia for individuals with severe disabilities and counselling for parents to “relieve them of their guilt” (Kennedy, 1942).

In reviewing early 20th century history on helping the parents of children with disabilities, it is evident that being the parent of a child considered “defective” is considered by some professionals as a kind of pathology in and of itself. Given an unquestioned acceptance of the connotation of disability as tragic, and related to death, disease and inferior genetics, it is not difficult to see why. These associations, and the language which support them, predate the early 20th century and remain the foundation of many core beliefs in our society.

Woodill (1994) describes seven popular metaphors as well as seven professional metaphors for disabled people which detail these various beliefs. Popular metaphors include disability as: misfortune, sickness, divine plan, punishment, threat, pet or entertainment and disabled person as other. Historically, popular metaphors are related respectively to: giving to charity, medical care, misfortune, sin, monsters, freak or horror shows and strangers. Woodill describes the representation of disability in professional discourses according to the following historically derived metaphors (derivations in parentheses): disability as a violation of norms (statistics), a deficit (compulsory education), misfortune (feeding those in need), a sign of sickness (tracking animals), an object of study (physics), a breakdown of functioning (assembly line production) and a technical problem (engineering).

Until recently, these beliefs about the nature of disability were seldom challenged. Many of them remain the dominant principles within particular professional and popular discourses today.

Specialized services continue to require IQ tests or other quantifying forms of evaluation. Medical research continues to look for the cause and "cure" of certain impairments. Employment issues are addressed through a focus on technical devices as the dominant way of accommodating physical impairments. Popularly, activities such as dwarf tossing continue to reinforce the metaphors that people with disabilities have value as entertainment. There are still telethons and charitable events designed to help "those less fortunate" which emphasize sympathetic views of people with impairments. People with disabilities are disproportionately poor (American Association of Disabled Persons, 1992; Barton, 1993) and are more likely to be the victims of physical and sexual abuse (Murphy and Corte, 1987; Sobsey and Varnhagen, 1994). In the next section of the review, I discuss challenges to traditional disability conceptions, as well as the emergence of the new metaphor of disability as a struggle for human rights.

Postmodern Stories About Disability and Parents

Following the Second World War, and perhaps because of it, thinking about the social world changed profoundly. The atrocities of the Nazi concentration camps and the atomic bombs dropped on Hiroshima and Nagasaki led many to question the notion that the dominant political and economic establishments were truly working in the interests of the larger society. Similarly, because it appeared to play such a key role in those events, the belief that science was benign and value free was seriously challenged (Parry & Doan, 1994).

Within this historical context, the awareness of the extremes to which eugenic thinking could be taken underscored a growing belief in the humane treatment and valuing of individuals with disabilities. The Nazis had tried to rid the world of Jewish people but they began their "eugenic experiment" by systematically exterminating people with disabilities (Wolfensberger, 1981). Early advocates of deinstitutionalisation and normalization often used the example of

Hitler's Germany to support their theories (Nirje, 1981; Wolfensberger, 1972). The post-war period was also a time for increased concern about the rights of marginalised and devalued groups within society. The language of the women's movement and the civil rights movement suggested a strong need to re-evaluate a world dominated by "white men with money" and an adherence to hierarchical values.

Within the post-war social context, one of the most influential theories in regard to people with disabilities, was that of normalization. Principles of normalization emerged in Scandinavia with Nirje (1970) and later in North America with Wolfensberger (1972). The new principles were guided by an ideology that saw institutionalization as dehumanizing and unjust.

Theoretically, normalization has much earlier roots in the rehabilitation movement. Normalization involved giving individuals with disabilities the patterns of a "normal" life (including a family or home life). It was strongly based on the notion that human dignity stemmed from being included and valued, and that being valued meant being seen as an active member of the community.

The emergence of normalization as a guiding principle in human services had a huge impact on the parents of children with disabilities. By itself, normalization had relatively little to do with counselling parents short of trying to get parents to examine the possibility of parenting their own children. Normalization suggested strategies for assisting individuals with disabilities in their day-to-day lives, growth and development. In practical terms, the implementation of the principle of normalization brought into question the value of the automatic institutionalization or segregation of individuals with disabilities. This meant that parents, for the first time in many years, were supported in their decision to keep a child with disabilities at home. The concept of normalization was not a constructivist or postmodern theory (Wolfensberger, 1995). It did however, set the stage for a very different kind of context in the lives of individuals with

disabilities and their families.

Current critical thinking about disability challenges the theory of normalization as taking for granted a set of assumptions about the value of normal patterns of life (Chappell, 1992). Others have commented that government promotion of normalization and inclusion has less to do with justice and more to do with saving money on expensive institutions and specialized services (Roehrer Institute, 1996). It is difficult to argue, however, that it did not open the door to the emergence of more critical theories because it brought to light centuries of oppression of people labelled with disabilities. It also meant that people with disabilities became visible participants in their communities. Concurrently, many people with physical and sensory impairments have developed their own versions of alternate constructions of disability. Shapiro (1993) cites the protests of the "Rolling Quads" and the "Gallaudet Uprising" as pivotal events in disabled political activism. These reflected, respectively, the experience of people with physical disabilities and people who are deaf.

The International Year of the Disabled in 1981 saw the culmination of this social change and began a decade in which definitions of disability and the services provided for people with disabilities would undergo radical alterations. Much of this change was fostered by individuals who had impairments. It was also the result of the actions of parents of children with disabilities (Singer & Powers, 1993). Although the politically active disabled community represents only a portion of the total population of people who are considered disabled, they have nonetheless become influential in public policy, research agendas and in the creation of services designed with their input. While the struggle for the recognition and the empowerment of disabled individuals is far from over, these ideas signify a radically different social context than existed prior to World War Two.

The remainder of the review of the literature looks more specifically at issues related to parents and parent counselling in light of this emergent context. The first example of literature on the counselling of parents, Olshansky's (1962) concept of chronic sorrow, is presented as a seminal theory in the development of approaches to the counselling of parents of children with disabilities. It is one of the first attempts, within professional literature, at defining their counselling needs. It is a modernist theory, rooted in taken-for-granted pathological assumptions about disability and being the parent of a child with disabilities.

Sad Stories - Chronic Sorrow

One of the first attempts to define the counselling needs of parents of children with disabilities was Olshansky's (1962) idea of chronic sorrow. Olshansky stressed the need for parents of children with severe disabilities to be able to vent feelings of sadness in order to "muster and maintain the stamina needed to live with the tragedy of having a mentally defective child" (p.192). He further cautioned the helping professional that the ultimate goal of counselling was not to foster acceptance of the child but rather to cope with frustration and stresses associated with a child's impairments.

From a critical perspective on disability, chronic sorrow can be deconstructed. Olshansky's (1962) ideas were based on the assumption of the presence of "defect" as having a universally felt psychological effect on parents. He described chronic sorrow as a "natural" reaction tied to "symbolic meaning on an unconscious level" (p. 191). The term 'defect' was a taken for granted assumption about what was normal. The connotation of that defect was tragic, and sorrow was seen to be a universally programmed emotional response in all humans. The conceptualization of chronic sorrow offered no discussion of the material or socio-political contexts in which these notions were embedded. The dominant social values of the time were

taken for granted as true.

In contrast to the assumptions of chronic sorrow, the following passage produced for new parents of infants diagnosed with Down Syndrome (DS) represents a contrary set of assumptions about disability.

If you are welcoming a new baby with Down Syndrome into your family, you probably have many questions and concerns as do your extended family, friends and neighbours... Allow your family, friends and neighbours some time to learn about Down Syndrome reminding them if necessary that DS is just a small part of who your child is and will become... You are allowed to feel however you feel and so are others who love you and your baby... take time to welcome and enjoy your baby. They grow up fast. (Wilson, 1996 p. 7)

This is not a tragic construction of disability, nor does it reduce the affective response of parents to a single emotion. Parents are "allowed to feel however they feel." The passage also suggests acceptance is both appropriate and desirable. It is significant that it is written by other parents and not an expert. In this respect, the information represents a different narrative about disability and parenting which fits within the framework of postmodern thinking.

It would have been difficult to imagine, in 1962, the idea that Down syndrome (or any other impairment) could be seen as "a small part of who your child will become," or that parents should welcome and enjoy their baby. Olshansky's (1962) theories and those of other grief stage proponents were, according to Bernier (1988), informed largely by psychoanalytic theory, specifically the idea that the birth of an abnormal baby was an assault to the ego creating a conflict with libidinal attachments. Zimmerman and Dickerson (1996) described psychoanalysis as modernist theory concerned with describing "exactly how things work" (p.15). The notion that

psychology could describe exactly how things work for the parents of children with disabilities is implicit in the work of Olshansky.

The concept of chronic sorrow continues to inform researchers in the subject area, suggesting it cannot be dismissed as a historical artifact. In a study of the counselling needs of parents of handicapped children, Kratochival and Devereaux (1988) found that, even what they termed "well adjusted" parents, continued to experience feelings of grief and the need to seek out counselling. In reviewing literature, I found a number of articles which continued to cite chronic sorrow as a relatively unquestioned conceptualization of the experience of parents of children with disabilities (George, 1988; Hornby & Seligman, 1991; Bernier, 1988). Within current theoretical literature, there are, however, more attempts to contextualize the concept of chronic sorrow. Oliver (1993) described what he termed the "fetishism for normality" as underlying the problems faced by parents in coming to terms with having a child with disabilities. From a constructivist position, the concept of chronic sorrow can be viewed as a particular discourse about being the parent of a child labelled with disabilities. It is not the only discourse, but it is reflective of dominant social values.

As another example of taken for granted assumptions, Glidden (1993), in a review of empirical studies, asked the question: "what parent would not wish for that disability to disappear and the child to have a "normal" life" (p.485)? In a recent conversation via a news group for parents of children with disabilities, I received a correspondence from a mother of a child with disabilities who stated " I would not want my son to magically have his disability disappear, because he would no longer be who he is. I would have a different child and I love the one I have." This may be a rare individual but it does answer Glidden's rhetorical question by showing that there is at least one parent who would not want her child's disability to disappear.

There are indeed many different stories about being the parent of a child with disabilities, and not all of them are about grieving and sadness.

Narrative therapists working from a constructivist theoretical orientation are concerned with what are termed "subjugating cultural discourses" (Zimmerman & Dickerson, 1996). Another description of this is stories derived by those in power to describe what is normal and not. Olshansky describes chronic sorrow as normal. Glidden suggests parents' longing for a normal child as normal. If these assertions are seen as absolute, then neither the parents of children with Down Syndrome, nor the mother of the child in the news group, are, in effect normal.

In summary, the concept of chronic sorrow was a seminal work in the area of counselling parents of children with disabilities. Important historically, this perspective recognized that parents of children with disabilities might benefit from some form of emotional support, rather than accepting the shame, concealment and abandonment characteristic of earlier views of disability. While the experience of chronic sorrow continues to resonate for many parents of children with disabilities, the construct of chronic sorrow is best understood in its historical and cultural context. Clearly, it is not the only story about being the parent of a child with disability, and from a constructivist perspective, it can be seen as a subjugating discourse.

New Stories About Parents of Children With Disabilities

Early attempts to define the counselling needs of parents of children with disabilities, like chronic sorrow, work from the modernist assumption of the single story. The single story tends to be sad and focuses on deficits. It takes for granted that parents' response to the birth or diagnosis of a child with disabilities is negative. From a constructivist perspective, the single story is a reflection of dominant cultural values. Foucault (1954) stated that "our society does not wish to

recognize itself in the ill individual whom it rejects or locks up; as it diagnoses the illness, it excludes the patient" (p. 63). Until the 1960s, the deficit or pathological model of disability - the "ill individual" - was seldom challenged.

More critical theoretical attempts to define disability and the relationships between disabled and non-disabled individuals include: the delineation of terms like "handicapism" (Bogdan & Bilken, 1977), an interest in the "sociology of acceptance" (Bogdan & Taylor, 1987; 1989) and theoretical constructions like the "politics of physical differences" (Hahn, 1988). Each of these studies addressed the shift from a negative evaluation of disability to a more positive one. In addition, popular metaphors of disability have emerged because people with disabilities are more visible and more active. While disabled hero worship can create problems for the majority of people with disabilities (Shapiro, 1993), the accomplishments of individuals like Stephen Hawking and Rick Hansen represent powerful contradictions to traditional tragic and dysfunctional views of disability. Even without citing examples of famous people with disabilities, people with disabilities have jobs, go to school, live at home and shop at the same malls as do people without disabilities.

Clearly, the social construction and acceptance of disability has changed or, at least, is undergoing a change. Disability is not always conceptualized as a "defect." It is seen, by some, as a challenge or as an opportunity to overcome obstacles. By others, disability is seen as the imposition of barriers by the dominant non-disabled society. Most importantly, disability is not just one thing. In the context of a more dynamic and evolving view of disability, the needs of parents necessarily reflect a more complex set of theoretical and practical issues. This social context includes the presence of supports for families where there were previously few, guarantees that children with disabilities receive appropriate education, and, in general, a concern

for the rights of individuals with disabilities. More simply, parents of children with disabilities are increasingly expected to be parents. In British Columbia and many other jurisdictions in North America, institutionalization is no longer an option.

Bigger Stories - Moving away from Pathology

The formal study of the counselling and support needs of parents of children with disabilities has evolved since the late 1950s and early 1960s. It tells a multidimensional story from a variety of perspectives, many of which are based on a more critical and deconstructed view of disability. The following review of key issues, concepts and findings is far from exhaustive. It is derived mostly from some of the larger reviews of the literature.

Considerable research on counselling parents addresses the stresses parents and families experience due to the presence of a child with disabilities. Researchers suggest this area of study has been troubled by both methodological problems and a lack of reliable evidence in defining and describing the stresses experienced by parents (Glidden, 1993; Hornby, 1994; Konstantareas & Homatidis, 1991). Much current research characterizes parenting stress as multidimensional and dynamic (Hanline, 1991; Beresford, 1994; Flagg-Williams, 1991). There has been a move away from conceptualizing all parents as experiencing the same stresses in the same way, and researchers have paid increasing attention to the issue of assumed pathology (Singer, Irvin, Irvine, Hawkins, Hegreness & Jackson, 1993)

Recent literature suggests that, as a population, the parents of children with disabilities experience no more or no less stress than parents of children without disabilities (Mahoney, O'Sullivan & Robinson, 1992). For instance, using a large sample of parents of children with disabilities (n=725), Innocenti, Huh and Boyce (1992) found no difference in stress scores between these parents and the normative sample of parents from the Parenting Stress Index.

Singer et al. (1993) cited the number of families experiencing debilitating levels of stress as roughly one third of all families of children with disabilities. In a meta-analysis of studies of the effects of a child with disabilities on fathers, Hornby (1994) found that little reliable evidence for eight hypotheses about paternal adaptation. For two other hypothesis, including a hypothesis about the relationship of income, education and social class to stress and the hypothesis that fathers of children with disabilities tended to desert the family more often, results were found to be equivocal. Bristol, Gallagher and Schopler (1988), in a comparative study of mothers and fathers of developmentally disabled and non disabled boys, found no directional relationship between the severity of a son's disability and parental adaptation.

In attempting to determine the impact of disability on parents or parental adaptation to having a child with disabilities, quantitative researchers have disconfirmed the single story that it is a universally sad and stressful story. The shift to a multi-dimensional emphasis addresses two other key concepts relevant to this study: a concern for the meanings attached to having and raising a child with disabilities, and attempts to frame the problem within a broader ecological perspective.

The work of Blacher (1984) and Allen and Affleck (1985) represent landmark studies in redefining the needs of parents for counselling and support. Blacher looked at previous studies that supported the notion that parents went through well-defined stages of adjustment, and found that the evidence was methodologically problematic as studies were based on clinical observations rather than controlled experiments. Furthermore, many of these findings simply could have been "attempts to perpetuate ideas from the literature" (p. 67), to prop up theoretical perspectives such as chronic grief and stage related theories of adjustment. Allen and Affleck (1985) sought to test the notion that stage-related theories were a case of stereotyping and found that "exceptional

variability in parents' responses may be more the norm than is a predictable pattern of adjustment" (p. 201). The authors went on to suggest that other variables, in particular the meaning parents attached to the presence of the child with a disability, showed greater promise as a way of conceptualizing the issue of parental adjustment.

Beresford (1994), in a significant review of the literature on how parents cope and care for disabled children, distinguishes between problem solving and emotion focussed coping strategies. In examining the effectiveness of emotion focussed strategies for reducing stress, he found conflicting and equivocal results. In contrast, problem solving strategies, in particular positive restructuring, more consistently yielded findings of beneficial outcomes. Positive restructuring, refers to changing the way the situation is viewed or, from a narrative perspective, telling a different story. This suggests that for, parents of children with disabilities, the construction of meaning around their child's disability plays a significant role in how well parents cope and adapt. In recent studies on the application of counselling interventions employing cognitive restructuring, Davis & Rushton (1991) and Davis (1985) found that, as parents did better on several measures of adjustment, their children also showed significant progress on developmental measures. It is difficult, however, to know the direction of effect implied by this finding.

Related to the idea of restructuring the reality of raising a child with disabilities is the notion of the context in which ideas emerge. Recent research literature also attends to issues of social ecology (Berry, 1995). This means placing the source of stresses within a contextual framework including macro-systemic issues of ideology, the development of social policy, and culturally based normative views on disability. This is significant to the present study since constructivist counselling theory is concerned with what Berry refers to as revealing the "realities" of the various "systems within people's stories" (p. 383). The problems of stress and

adaptation for parents of children with disabilities is not entirely a problem of the individual but is external to person and located within the larger cultural discourse.

This concern for constructed realities is also a key feature of the growing disability rights movement. The next section of the literature review frames the argument for a more critical approach to studying the experience of parents of children with disabilities from the perspective of individuals who themselves have been labelled with disabilities.

Provocative Stories - It's Okay to be Disabled

An emergent critical discourse within the field of disability studies includes the work of disabled political activists. The title of this section is taken from an article by Shapiro (1995), editor of the Disability Rag, a periodical about disability written from the perspective of individuals with disabilities. Disabled activism, as compared to other social movements (gay and lesbian rights, the women's movement and environmentalism), is relatively recent.

Writers working from this position discuss the subject of disability in what many non-disabled individuals might view as provocative ways. The slogan "it's okay to be disabled" parallels "we're here, we're queer - get used to it." Unlike the gay rights movement however, the disabled rights movement has received much less attention. The idea that it is okay to have a disability continues to be controversial. This may be particularly so as experienced by parents of children with disabilities. There is an ideological legacy of deficit conceptions of disability, as well as a subjugating social construction of parenting, which stresses that parents are successful when their children are accomplished, able-bodied and "normal." This is what Oliver (1993) describes as a "fetishism for normality."

In reviewing the critical literature on disability, there are a number of examples of narrative accounts by children with disabilities about their parents and families. The importance of

these stories with respect to the current study is that they describe particular versions of subjugating stories, specifically in regard to issues of fixing, concealing and protecting individuals with impairments. The first story is an account by a writer with a visual impairment:

Some of my earliest memories are of anxious relatives trying to get me to see things. I did not understand why it was so important that I should do so, but was acutely aware of their intense anxiety if I could not. It was aesthetic things like rainbows that bothered them most.”(French, 1993 p.69)

French goes on to relate that at one point in her childhood she simply started pretending to be able to see the rainbow. She internalized the dominant story that not to be able to see was dysfunctional and disturbing. The intense anxiety of her relatives maintained the problem-saturated story of visual impairment. If the subjugating nature of this discourse on disability had been unmasked sooner, French contended that her experience in denying her own reality might well have been less painful.

The second example describes what could be called the “hide-it-away” story about being the parent of a child with disabilities. The following passage is from the play, Creeps, by David Freeman, a writer with cerebral palsy:

What do you guys know about the bullshit I put up with? My old lady, now get this my old lady has devoted her entire goddamn life to martyrdom. And my old man...Wait'll ya hear what happened last night. He invited his boss over for dinner and you know where the old bugger wanted me to eat? In the kitchen. (Freeman, 1971, p. 10)

While this passage is a literary example, it is informed by Freeman's experiences as an individual labelled with a disability. Again, it brings to light the influence of old stories, in this case, the

negative influence of stigma and shame. As discussed earlier, the concealment and shame of having given birth to a child with disabilities was at one time a dominant assumption by professionals and the general public.

The third example is from a qualitative study conducted by Bogdan and Taylor(1982) which involved in-depth interviews of two formally institutionalized individuals labelled with mental retardation. One of the subjects, Ed, describes his experience with his mother:

The doctors told my mother that I would be a burden to her. When I was growing up, she never let me out of her sight. She was always there with attention. If I yelled, she ran right up to me. So many children who are handicapped must be in that position - they become so dependent on their mother. Looking back I don't think she ever stopped protecting me, even when I was capable of being self-sufficient... She never really believed... that I could be like everybody else.

(Bogdan & Taylor, 1982 p.31)

This passage demonstrates the theme of protection. It also places it in the context of parent professional relationships, referring to the doctor's admonition that the child would be a "burden." Despite Ed's ultimately successful attempt to be self-sufficient, his mother's relationship is still informed by the subjugating discourse that having a mental handicap equals dependency.

These three examples are illustrative of how the issue of having a child with disabilities can be constructed according to a set of assumed realities. The presentation of these examples is not meant to suggest stereotypes of parents of children with disabilities as callously rejecting, neurotically over-protective or thoughtlessly in denial. Pointing to examples of problem-saturated narratives has the effect of suggesting alternative stories. It is okay to not see rainbows, acceptable to be in a wheelchair and possible to be self-sufficient despite taking longer to learn

things.

Kunc (1992) contends that, "we live in a society that holds forth belonging as something that is earned through academic or physical achievement and a host of other socially valued criteria. Belonging is no longer an inherent right of being human" (p. 6). The preceding stories speak to the need to belong and to be accepted as a fundamental need which is often denied to people with impairments. The critical discourse on disability and family is about unconditional acceptance. This represents a stark contrast to Kennedy's (1942) and Olshansky's (1962) admonitions that the encouragement of parental acceptance of children with disabilities was futile and unrealistic. The stories of individuals with disabilities, based on these examples, suggest that, not only is parental acceptance desirable, but that it should be a right of all humans regardless of ability .

To conclude this section, a quote by Turnbull (1988) is presented to suggest that elements of the critical discourse on disability are already being discussed in the literature on counselling parents and that this dialogue has begun to revolve around issues of unconditional acceptance.

I will never forget the conversation with the mother of a daughter with Down Syndrome who shared with me the profound revolution in her thinking when it occurred to her when her child was seven years old that she could be whole in her eyes and she could love her for whom she is today rather than whom she might become. A challenge for us to consider in conceptualizing family support is how to make this revolution happen much earlier and prevent that mother and many others from the heartache and detachment of not being able to love unconditionally a child with a disability (p.265).

Another example of parents in a different revolutionary mode, can be seen in "the Mothers

From Hell” who are “ a loose-knit...group of women who staunchly advocate for the rights of our children with disabilities” (Gerlach, 1996). Parent activism represents a variation of Turnbull’s “revolution” and similarly, points to another possibility for telling a different story. The Mothers from Hell advocate the use of humour as a way of making sense of their life situations. Their story speaks to the fact that some parents have come a long way from tragic and deficit views of having a child with a disability. In the next section of this review the idea of telling “different stories” is explored in greater detail.

Different Stories - The Case for Constructivist Counselling

In a qualitative study by Knoll (1992), the parent of a child with disabilities describes her son: “Robbie is truly a blessing. People in our lives, because of Robbie, are people we learn from, are inspired by... As things work out I couldn’t be happier” (p. 35). Chronic sorrow does not appear to be a central concern in this parent’s experience with her child. Examples such as these point to the fact that there are parents of children with disabilities who have re-authored the tragic narrative. Considerable recent research has examined and detailed the positive adaptation of parents and families of children with disabilities (Beavers, Hampton, Hulgus & Beavers, 1986; Trute & Hauch, 1988; Mahoney, O’Sullivan & Robinson, 1992; Bennett, DeLuca & Allen, 1996).

The title of this study refers to telling different stories. This is also meant to be a play on two meanings of the word different - different (alternative) stories about being different (not like the majority). This is one of the central issues of both constructivist counselling theory and critical postmodern theories in the field of disability studies. From the latter perspective, disability is seen to have been historically and socially constructed as a mostly negative problem of individual adaptation. The alternative story is that disability is a feature of social and ideological structures

constructed, in part, in order to maintain subjugating belief systems about human normality and human ideal types (Kiel, 1995). People with impairments are excluded or rejected, not because it is for their own good, but because it gives validity to the dominant narrative of how people are “supposed” to live.

To a degree, medical and bureaucratic narratives on disability continue to construct disability as an individual pathology focussing on deficit and dysfunction (Humes, Szymanski & Hohenshil, 1989). Some of the articles reviewed for this study appeared to work from this perspective, referring for example to things like “the stresses created by the care of a retarded child” (Abbott & Meredith, 1986). While having a child who is intellectually different than others poses challenges for parents and many of those challenges are stressful, the linking of that stress to the disability is problematic from a critical perspective. Being “retarded” is a clinical label for a condition of having limited cognitive abilities. It means thinking processes are slower than a statistical norm, in as much as those processes are measured by standardized IQ tests. The stress created by the care of the child is not a feature of retardation or the “retarded child”; it is also grounded in the ecology of a society that values the ability to read and write, to think quickly and efficiently and to behave according to established rules of behaviour. When that child is viewed as being acceptable for being simply who he or she is, including cognitively, then the different story may be far less stressful.

In a qualitative study, Bennett, Deluca and Allen (1996) noted that parents felt that positive acceptance of their children, despite their disabilities, was a key component of positive adaptation. This is an interesting finding, considering that, in more traditional perspectives on the counselling of parents of children with disabilities, working towards ultimate acceptance of the child with disabilities is seen to be “unfair and unrealistic” (Bernier, 1988, p. 595). In that

prejudices can take a long time to deconstruct, counselling parents towards ultimate acceptance might have negative ramifications. From a more critical perspective, however, how fair is it to relegate children to a problem-saturated narrative where they internalize a sense of their own difference in the world as being the result of something fundamentally and intrinsically dysfunctional or undesirable about them? And, similarly, how fair is it to parents? Is not the statement, "I couldn't be happier" better, and ultimately more productive than the ideas embodied in the concept of chronic sorrow? Further to this, what purpose does counselling serve but to help people be happier?

These questions may be rhetorical, but they are also pragmatic. The empowerment of parents derived through a re-authoring of their relationships to the "problem" of disability, has the potential to change both the quality of family life and the value of people with disabilities within the larger society. At least, it presents one less barrier. For a counsellor or other support person, this does not have to mean directing parents towards some artificial sense of acceptance, but instead can take the form of exposing parents to a variety of stories about being the parent of a child with disabilities.

In this review of the literature, I have traced the historical context of the counselling of parents of children with disabilities from an older view reflecting a set of single stories (rejection and chronic sorrow) to the more current critical perspective that accepts many stories, and more positive ones. I have also discussed dynamic changes in the social construction of disability, and suggested that perhaps the most important variable in how parents resolve issues of having a child with disabilities is ontological rather affective. Finally, I have considered the experiences of children with disabilities that suggest that old stories about being the parent of a child with disabilities need to be, and can be, deconstructed in favour of more positive, hopeful and

empowering ones.

With respect to new stories about being the parent of a child with disabilities, deconstruction presents a useful framework for understanding the process of change and what kinds of counselling interventions might be appropriate for parents. Micheal White (1991) describes deconstruction in therapy as an active process with the intent of helping people take control of their problems, rather than letting their problems control them. Disability, in the socially constructed sense, is a problem and like other problems it has its own way meddling in people's lives. As a problem, it is supported by a dominant discourse that constructs the reality of being disabled as problematic, negative and stressful. However, many people are beginning to author different stories about disability that contradict and challenge the old story of tragedy and pain. These new stories point to alternative solutions where impairment is no longer constructed as a problem. A person who actually travelled all over the world in a wheelchair, the Mothers From Hell, and Robbie's parents who came to see him as a joy rather than as a burden are representatives of these new stories.

Zimmerman and Dickerson (1996) introduce their book on narrative therapy with the statement, "we're not in Kansas anymore" (p. 9). This statement represents their metaphor for the paradigm shift in counselling from a modern to a postmodern context of inquiry. "Kansas," for the parents of children with disabilities, is the world of chronic sorrow and deficit descriptions of disability. While many parents go back there from time to time, there are many more places to explore. The present study seeks to expand on the idea that parents indeed have a greater range of stories to tell.

The Research Questions

In the review of the literature, I have detailed several key issues relevant to the counselling

of parents of children labelled with disabilities. Most importantly, I have put forward the position that there are a number of discourses on being the parent of a child labelled with disabilities. I have also described constructivist counselling practise with particular attention to the theoretical principle of deconstruction.

Hypothesis

The stories of parents of children labelled with disabilities about their own processes of adaptation, growth and coping deconstruct the dominant discourse on disability and its effect on parents.

Research Questions

1. In what ways have these parents of children with disabilities deconstructed the dominant social discourses about being the parent of a child labelled with disabilities?
2. With regard to counselling and support, do these parents' stories identify assumptions made by help-givers based on dominant constructions of disability? Do these assumptions impact negatively on the counselling and support they receive?
3. What are the particular kinds of "problems" that these parents identify which form the content of counselling? For example are they concerned with issues of their own grieving and sadness or are they concerned with issues of making sense, reframing perceptions and reauthoring their experience, or are there other main focuses?
4. Are the constructivist theoretical principles of narrative therapy relevant and useful in the practise of counselling parents of children with disabilities?

CHAPTER 3

METHODOLOGY

Design

This study used a focus group design with three groups of parents of children labelled with disabilities. I collected qualitative data in the form of parent narratives about their experiences raising a child with a label of disability. The focus group method is described by Stewart and Shamdasani (1990) as a group interview suited to producing “a rich body of data expressed using the respondents’ own words and context” (p. 6). As a qualitative method, Morgan (1988) sees focus groups as combining the advantages of participant observation and individual interviews. As well as gathering content information, researchers are able to observe the dynamics that exist within a particular group. This study focused on content and the dynamics of how particular stories are constructed or deconstructed rather than on the interpersonal dynamics of groups of parents of children with disabilities.

Participants

Study participants were a sample of convenience of parents of children with disabilities (n=15). Two groups (n=7 & n=3) were recruited in Lakeville¹ and one (n=5) in Mill Town British Columbia. One of the groups in Lakeville (n=3) was recruited through the local Child Development Centre (CDC) and was not a pre-existing support group, whereas the other two groups were pre-existing support groups for parents of children labelled with disabilities. In contacting participants for the CDC group, the assistance of centre staff was utilized. They contacted participants individually and gave them an opportunity to ask questions about the study prior to making a decision about participating. In the case of the existing support groups, the

¹ Community names throughout the study are pseudonyms.

moderator met with or contacted a representative (rep) of each of the groups to explain the study, to answer questions and to provide informed consent forms for the rep to take back to the group. Support group members gave permission to the group rep to provide names and phone numbers to the moderator. The moderator contacted group members individually to arrange the interview date and time for the Mill Town group. In Lakeville, the rep recruited participants and arranged the interview.

In order to determine the characteristics of the focus group participants in this study, a brief questionnaire requesting demographic data was completed by all participants (see Appendix A). This information was intended for descriptive purposes only. A summary of demographic data is presented in the results section and in tabular form in Appendix B. Table 1 presents a breakdown of participation and recruitment for each group. The numbers in brackets are the numbers of parents who had originally agreed to participate in the study.

Group	number of parents	number of families	number of children with disabilities
Mill Town (MTSG)	5 (7)	4 (5)	4 (5)
Lakeville (LVSG)	7 (9)	5 (6)	5 (6)
Lakeville (LVCDC)	3 (7)	3 (6)	6 (9)
total	15 parents (23)	12 families (17)	15 children (20)

Table 1 - Summary of Participation and Recruitment

In all three groups, more parents were recruited than actually participated. With the Lakeville and Mill Town parent support groups, this was due to difficulties in accessing babysitting. In the Lakeville CDC group, seven parents were originally recruited for the focus group. Four of the parents who had agreed to participate in the study cancelled at the last minute due to illness and family emergencies. Rather than rescheduling the group, the interview proceeded with three parents.

The sampling approach was also purposive in that it sampled intact groups of parents who are engaged in a therapeutic setting and who have already shared some of their experiences. While participants in the Lakeville CDC group were not in a pre-existing support group, they were acquainted with each other through various educational programs at the centre. This minimized the impact of participants' discomfort in sharing personal stories and suited a focus group methodology as there was already a pre-existing group dynamic. As stories about coping and adaptation are the focus of this study, parents who had joined a support group were an appropriate target population. The use of three focus groups gathered more narratives representing a variety of parents of children with disabilities. Parents' children were at various developmental stages and had various types of impairments. These groups included three fathers, an adoptive couple, one foster parent and ten biological mothers. One limitation of the convenience sampling was that all of the parents' children in the two parent support groups were female.

Procedures

Focus groups typically are structured as a moderated discussion with relatively fewer questions than an individual interview. Individual responses to questions as well as the discussion of issues between participants are the usual sources of data. The present study, rather than using a set of predetermined questions, used a two dimensional questioning protocol derived from narrative therapy. This involved attention to two principles of narrative therapy - externalization of problems and the use of deconstructive questioning. All focus group sessions were audio-taped and transcribed and were conducted with the assistance of a co-moderator. Focus groups sessions were conducted in local college or university meeting rooms. I was the primary moderator for the interviews.

Focus group sessions began with an introduction and a warm up activity involving having participants introduce themselves with information that assisted moderators in remembering individual's names. This was intended as an ice-breaking activity to facilitate participant comfort and to set the tone for the session. As an exception, icebreaking was not deemed necessary in the Lakeville Support Group as all but one of the participants and the moderator were previously acquainted. The moderator provided an overview of the session detailing the purpose of the study and explaining ethical safeguards in the study. Before proceeding to the first phase of the interview, participants were given the opportunity to ask questions.

I began by asking participants to share with the group their experiences in raising a child with disabilities. The question - what has been your experience in raising a child labelled with disabilities? - was the only predetermined and specific question used in this study. This was deliberate. The participants determined the content of subsequent discussions. This was in keeping with Kreuger's (1994) notion that focus groups work best with a broad open-ended question and a moderator who has good group facilitation skills and an awareness of interpersonal dynamics.

The study was premised on the idea that counsellors cannot presuppose issues of content. In order to ensure that participants were being provided the chance to determine the subject matter, probe questions were open-ended and focussed on the purpose of the study. Probe questions were used infrequently in all three of the interviews since parents had a great deal of information to share. Where probes were used, they tended to elicit elaborations of issues that parents had already brought up. Throughout the sessions, it was reiterated that parents were free to discuss any issue they wished. In some of the discussions the moderator also engaged parents by sharing related stories. This was done only in relation to issues that parents had already discussed. Sharing stories also helped to establish a level of comfort for parents. The tone of the

sessions was relaxed and informal.

During the early stages of the interview, I listened, reflected and clarified statements made by parents. This ensured that specific content was determined by participants and was not being introduced by the moderator. The co-moderator recorded broad themes or topic areas in a notebook. Notes were later used to summarize the discussions. They also provided a written account of the interviews that was useful during the analysis of the data.

During the interview, I attempted to refer to problems or issues using externalized language. Externalization is a key aspect of narrative therapy. As discussed in the literature review, externalization refers to the process of describing problems as external to the individual rather than locating problems within the person (White, 1990). For example, when parents brought up the issue of difficulties in looking for support, the issue was discussed as the problem of looking for support rather than as your difficulties in looking for support.

At the end of the interviews, participants were asked to come to a consensus ranking of three of the most pressing or important problems or issues. The prioritization of themes sought to answer the question what kinds of problems or issues parents identified as important for counsellors. The use of prioritization provided a measure of validity as it summarized and clarified the content of the discussions.

Use of Deconstructive Questioning

Throughout the interview, it was my intent, whenever possible, to ask questions that facilitated parents' deconstructed views. Examples of deconstructive questioning included such questions as: How has [the problem] affected you in the past and how has your relationship to [the problem] changed? How do you think other people's ideas about how [the problem] is supposed to affect parents of children with disabilities strengthens [the problem's] position? How

has your involvement with [the problem] influenced how you look at other people? When [the problem] came into your life how did it take over? How did you finally defeat [the problem]? Where deconstructive questioning was used, it involved the use of the question how did that (the problem or issue) change?

These questions were derived from the therapeutic questioning process of narrative therapists (Zimmerman & Dickerson, 1996; Parry & Doan, 1994; White, 1991). They were modified to fit with both the content of this study and with a focus group methodology. The intent of this study was not to provide therapy to parents, but to engage parents in a discussion about the therapeutic change process as they have experienced it. The purpose of deconstructive questioning was to bring into the discussion an awareness of how problems are maintained in relationship to dominant social discourses. It was evident early in the first interview that parents' narratives already provided responses to these questions, so deconstructive questioning was used less than was originally intended. The use of the questions during the actual interviews felt artificial.

In summary, the interview process included: an open-ended elicitation of the parents' narratives about raising a child with disabilities; attention to the externalization of issues or problems which stemmed from that narrative; the prioritization of the top three issues of importance to the parents and; the attempted use of a deconstructive questioning process or protocol. I used open-ended questioning and did not attempt to introduce specific content into the discussion. For the most part, parents engaged actively in the interview process, had a number of issues they wanted to discuss and provided little opportunity for the moderator to ask questions. The use of deconstructive questioning involved being aware of how parents had defeated or changed their relationship to a problem. In some cases, this was as simple as asking, "How did

that change?

Roles of the Moderators

As the moderator in this study, I introduced and facilitated the focus groups. The role of the co-moderator was primarily as a procedural support person. She recorded information on a flip chart or notebook, assisted with the rank-ordering of problems and acted as an observer. Following the sessions the co-moderator and moderator debriefed the interview process, noting inconsistencies in the application of the interview process, sharing observations about how specific questions did or did not work as well as clarifying observations on issues related to group dynamics and the content of parents' narratives.

The co-moderator was a fellow graduate student in counselling who is familiar with narrative therapy theory and practise. I provided her with a training session that reviewed and rehearsed the interview process and her role in it. An interview guide developed for this study specifically delineates the moderator and co-moderator's roles. (see Appendix C).

Ethical Considerations

Ethical considerations included issues related to the differentiation of counsellor/researcher roles, my position as a professional providing services to individuals with disabilities in the same community and the potential risks associated with the disclosure of personal information of individuals within a group setting. Each of these was addressed in the informed consent letter (Appendix D), which participants received and returned before the study was conducted. A brief elaboration of these issues follows.

Participants were informed that the purpose of the focus group was to gather information for an academic study and not to provide counselling. It was, however, acknowledged that there was a therapeutic benefit to their participation. Participants were informed that they did not have

to disclose anything they did not feel comfortable sharing and that if they did experience difficult emotions, these would be de-briefed following the session. Agencies assisting in the recruitment of participants were informed of the nature of the study and these potential risks beforehand and agreed to be available if needed.

Some participants were the parents of current, past and potential students in the program I teach. Group members with whom I had a pre-existing relationship were addressed on an individual basis clarifying that my role was research-related rather than tied to my role as an instructor at the college. Participants who knew me were encouraged to hold back any information they felt created a conflict for them because I knew their child. None of the parents in the study were currently enrolled in my program although three had prior experience with me as a teacher.

Participants were informed that they and their children would be assigned a pseudonym in the finished study and that if a unique aspect of their child's disability was seen to identify them, this would be addressed on an individual basis. Two parents gave information that they believed might inadvertently identify their child in the finished study. In these cases, their children's specific diagnoses have not been named. In addition to this, the names of particular agencies have been glossed or not mentioned in relation to a specific community, especially if a parent's statement could be seen to be critical of that agency. Names of schools, similarly, have been glossed in the final report of the results and names of other people not present at the interview have been assigned a pseudonym.

Data Analysis

The first step in the data analysis process was to compile and summarize the facilitators' debriefing notes from each group session. I reviewed whether the sessions followed the same

process and made key observations on people's reaction to the process. I compiled demographic data from the questionnaire for each group and as a whole sample and summarized the topic areas from the consensus-ranking phase of the interview. Group demographics were compiled and noted for descriptive purposes only.

Interviews were audio-taped using multidirectional microphones on standard cassette tapes. In each interview, an additional tape recorder was used as a back-up. One of the taped sessions (LVSG), utilized a different type of microphone and recording system than the other two groups and was not as easily heard on the finished tape.

An assistant completed the initial transcription of the tapes, saving each interview in a separate computer file. Using a hard copy of each interview, I listened to each interview two more times and filled in details that the transcriber missed. Some of the dialogue was not transcribed, either because there were too many people talking at once, or because cassette tapes were being changed while parents spoke. The quality of the taping was generally good so very little of the interviews were missed.

For the purposes of this study, I have not made between group comparisons. Instead, the thematic analysis treats the interviews as one unit. Some descriptions of intergroup differences are mentioned in the result section but this was not a major focus. Interpretation of the data involved noting how the content of parents' dialogue compared and contrasted with central topics in the professional and academic literature. Analysis also located specific statements and themes which suggest that parents' views were or were not a deconstruction of the dominant discourse.

Once the interviews were transcribed, analysis involved sorting specific passages, statements and bits of dialogue into themes. Sorting was accomplished through a cut and paste procedure using WordPerfect 6.1 for Windows. Separate computer files were created for each theme. Interview files and theme files were able to be open simultaneously. Once statements were

cut from the interview, the interview file was saved with the sorted passages removed. Cutting and pasting continued until each interview file contained either indecipherable dialogue or unrelated bits of conversation (e.g., one of the groups discussed the Olympics).

There were three rounds of sorting, recombining and categorizing themes. In round one, 25 themes emerged. These were resorted and recombined into 11 themes in round two. In round three, following an analysis using deconstructive criteria and a first draft of the results, themes were refined and, in one case, re-split into 13 themes. Table 2 summarizes the three rounds of sorting.

Round 1 25 themes	Themes included: community relationships, horrible pictures, larger discourses, comparisons, grief, guilt, stress, diagnosis, getting services, government, humour, independent living, interventions, medical issues, normal parenting, other family members, other parents, barriers, positive outcomes, parent essentializations, parent professional relationships, school, siblings, support groups, waiting
Round 2 11 Themes	Five themes combined several of the original 25 into five broader themes. These included: meeting children's needs, affective issues, parenting stories, bureaucracy and supports. Six themes remained intact from the first round. These were: barriers, siblings, larger discourses, horrible pictures, comparisons and diagnosis.
Round 3 13 themes	These themes included: The six intact themes from the previous two rounds and four of the combinations from round two. Two themes (parent essentializations and assessments of normal parenting) were separated from the combined theme of parenting stories in round 2. The final theme, non-pathological views, was created as a new theme at this point. Three of the themes (siblings, supports and barriers) are not presented in the results chapter

Table 2 - Summary of Thematic Sorting

Ten of the final 13 themes were then assigned to one of four categories of stories: stories about assumptions, stories about dealing with difference, stories about professionals and stories about disability. The choice of the term stories was in keeping with a narrative therapy perspective. This final categorization of themes was done in order to provide conceptual organization. The decision on these final categories evolved through a process of locating the dominant ideas within each theme. Stories about assumptions and stories about professionals were

fairly straight forward categorizations. Horrible pictures and parent essentializations are about other people's assumptions. Meeting the child's needs and bureaucracy are about professionals and professional discourses. The other two categories took more thought and several other possibilities were tried before deciding on stories about difference and stories about disability. Categorical criteria are elaborated in the results chapter.

The creation of themes was bounded in three ways. First, six of the themes were simply topical. Parents mentioned or discussed the subject of the theme in their conversations. The sorting process, in some instances, utilized the search function of the word processing program. Topically derived themes included: affective issues (guilt, grief, humour), meeting children's needs (a number of sub-themes), bureaucracy, diagnosis, siblings and supports.

Five themes were deductively derived from criteria based on principles from constructivist theory and critical perspectives on disability. Specifically, these were: the attention to historical discourses, the idea of culturally subjugating discourses about disability (horrible pictures), the idea of essentializations, the concept of barriers and deconstructions of assumptions about parenting. The theme of comparisons was both topical and theoretical. Parents discussed the topic of comparisons in some cases and in other cases I have interpreted their statements as being a comparison of their child to other children. The final theme, non-pathological views, was constructed as a category of summative or general statements about the experience of raising a child with disabilities.

Narratives were compared with existing theoretical knowledge in the area of counselling parents of children with disabilities and gleaned for specific examples reflective of deconstruction. Using a hard copy of the sorted themes, I wrote notes, highlighted specific sentences, and compared specific themes to specific concepts from the literature review. This

process also involved noting my evaluation of parents' narratives and being careful in being open to other perspectives. Since the completed sort involved looking at over 300 specific passages, not all of the data are reported in detail.

The criteria for determining whether a statement reflected deconstruction was as follows:

1) the statement questioned or dismissed what was offered as legitimate knowledge and was perceived by the narrator as a cultural value or assumption; 2) the statement appealed to individual validity of interpretation rather than "widely held beliefs;" 3) the statement pointed directly to a contradiction with taken-for-granted assumptions about the nature of the phenomena in question; or 4) the statement contextualized or reframed the issue. Examples of deconstructive statements were mentioned in the literature review - tragedy is in the eye of the beholder, it's okay to be disabled, you are allowed to feel whatever you feel. Non-deconstructive or essentialized statements or ideas include: What parent does not wish that their child could be normal?, having a defective child is tragic, or feelings corresponding to a pattern. Statements which did not fit the criteria of deconstruction were generally those statements that tended to appeal to the notion of "accepted wisdom." For example, one of the parents in the study referred to guilt as "something every parent of a child with disabilities experiences."

In addition to these criteria, I looked for examples of statements which suggested the presence of a subjugating cultural discourse, or, more precisely, other stories or discourses that parents perceived had a negative effect. In this regard, I paid particular attention to parents' criticisms of and comments about professionals, professional discourses and popular metaphors about disability. This analytical framework was derived from Berry's (1995) idea about revealing the realities of systems within people's stories, as well as Woodill's (1994) description of popular and professional metaphors of disability.

The overall approach to data analysis is similar to Addison's (1992) description of grounded hermeneutics. A key aspect of hermeneutic research, according to this author, involves offering "a narrative account of how a problem is developed and is maintained; and offer(ing) directions for positive change"(p. 113). This process is interpretive, subjective and unapologetically biased or grounded in a particular theoretical or philosophical position. It should be emphasized that while I have attempted, as much as possible, to act as a conduit for these parents' stories, I have done so through a particular theoretical and philosophical lens. My position on disability is that impairment need not be dysfunctional nor tragic, but that it is socially and historically constructed as such, often to the detriment of individuals who have impairments.

To provide some measure of interpretive dependability, examples of parents' stories presented in the results were reviewed by an independent observer together with the criteria for ascertaining whether a statement represents a deconstructive statement. The observer was an individual with no prior knowledge of the content of this study but who was familiar with narrative therapy techniques and critical constructivist theory. The results of this dependability checking are discussed in the next chapter.

In addition to the interpretive dependability check, the dependability of the thematic sorts has been determined by providing another independent observer with a selection of the statements presented in the final analysis together with the theme and a brief description of how each theme was derived. The observer was asked to sort the statements into their various themes. These were then compared with my own analysis. The individual in this case is an individual with a background in special education and a number of years of experience working with individuals with disabilities and their parents.

In summary, the analysis of data included: 1) a compilation of demographic data,

facilitator debriefing notes and information from the consensus-ranking phase of each interview; 2) audio-taping and transcribing the focus group sessions; 3) three rounds of sorting statements and passages from the transcripts into 13 themes and a combining of 10 of these themes under four broad categories; 4) analysis of the themes using criteria for deconstructive and non-deconstructive statements as well as a grounded approach tied to the constructivist idea of subjugating cultural discourses; and 5) interpretive and thematic dependability checks by separate independent observers.

CHAPTER 4

RESULTS

In this chapter, before proceeding to a detailed description of each category, theme and sub-theme, I present a summary of demographic information and the results of the dependability checks. The chapter concludes with a discussion of issues that parents did not deconstruct and an overall summary of the results.

Summary of Demographic Information

The children of parents in the focus groups were at various stages of development. The oldest child represented was 30 years old and the youngest was 18 months. Three married couples participated in the study so there were 12 families represented. One couple were adoptive parents of a child with an acquired impairment. There was one foster mother of four children with various impairments. The rest of the participants were the biological parents of their children. There were 3 fathers and 12 mothers. The majority of parents, 10 of the mothers and 2 of the fathers, were biological parents.

In total, parents' narratives represent experiences with 15 different children. Children's primary impairments included physical (n=4), developmental (n=8) and learning disabilities (n=3). Of these, 4 children had multiple impairments including one who was visually impaired. Five of the children had been diagnosed with specific genetic conditions which are not named in the study to avoid identifying the parent and the child. All but 2 of the children had congenital conditions of impairment.

One of the couples in the study was Asian. The remainder of the participants were European- Canadians. Two participants were single parents; 1 of them was a widow. More than

half (n=7) of the families had combined incomes over \$50,000 per year. Two single parents had incomes under \$20,000. Most of families (n=8) had 2 siblings, including the child with disabilities. One parent had only the child with disabilities and 3 families had 3 children. The foster mother had 3 biological children as well as 4 foster children with disabilities. While data on the age and gender of the children was not requested with the use of the demographic survey, information from the interviews revealed that 5 of the children were of preschool age, 5 elementary school age, 2 high-school age and 3 were adults. Ten children were female and 5 were male.

The majority of parents (n=8) had some college or technical training. Four parents had some university education and 1 a bachelors degree. Two of the parents reported that the highest level of education they had attained was secondary school graduation. Two parents were between the ages of 25-34, 7 parents between the ages of 35-44, 4 parents between the ages of 45-60 and 2 parents were over 60 years of age.

Parents reported various combinations of prior experience with emotional and psychological supports. Only 4 of the parents reported seeking out the services of a trained counsellor. The most common supports were those provided by family or friends (n=11) and other kinds of professionals involved with their children (n=11). Ten parents reported seeking out the emotional support of other parents of children labelled with disabilities, while 2 said they had not sought psychological or emotional supports. A detailed summary of demographic data is presented in Appendix D.

Validity and Dependability of the Results

The results of this qualitative analysis are grounded in a constructivist theoretical and philosophical orientation. The validity of these results relates to the authenticity of parents' perspective, the depth and clarity of parents' individual stories and the dynamic nature of focus

group interaction. In the case of the latter point, details in many of the interviews emerged in relation to discussions between group members and similarities in content between the three groups. In analyzing the results, I have attempted to act as a conduit for these parents' stories. The authenticity of these results, in part, relates to the open-ended nature of the stimulus question. Parents were asked to share whatever they thought was relevant. I made a conscious effort not to introduce content during the interview. The use of multiple observations (3 groups) with parents of children with different kinds of disability and at different stages of development provided a breadth of perspective. The consensus-ranking of issues was also a way of enhancing validity. Through three rounds of sorting and categorizing, themes were clarified and better defined.

The interpretive dependability check resulted in the coder concurring that 24 of 28 (85%) statements represented one or more of the criteria for deconstruction (see Appendix E). This is an acceptable level of inter-rater agreement. He also related that some of the selected statements were difficult to assess because they were presented out of context and because he also did not have a background in disability-related issues. He added that the criteria, as they were presented to him, were not altogether clear. This suggests that, by clarifying criteria and providing a training session for coding, inter-rater dependability would have been higher. It would be helpful as well to complete the check with other observers.

The test of dependability of the thematic analysis involved having a different coder sort 20 randomly selected statements into the themes presented in this study. This observer concurred on 12 of the 20 statements after reviewing statements once. The eight non-concurrent statements were reviewed again by the observer and of these six were concurrent with the observers second choice. I believe that this inter-rater agreement is more reflective of insufficient clarity of the

coding definitions and the lack of training of the coder than of lack of dependability of the thematic analysis. It is not surprising, given that I have contributed a great deal to the construction of this thesis, that another observer would express a different perspective.

Parents' Stories

Within all of the interviews, parents discussed a number of issues related to their experiences in raising a child labelled with disabilities. They provided richly detailed anecdotes about the struggles they have faced as well as the rewards they have gained. In telling their stories, these parents reflected on wider social issues, related provocative and positive statements about some of the professionals who are in their lives and shared their frustrations, sorrows and joy poignantly, honestly and often with humour. In the end, the focus groups provided a broad forum for parents to discuss a wide variety of issues. While there were some inconsistencies in the application of the interview process, these parents had many stories and welcomed the opportunity to tell them.

Working from a critical constructivist framework, four broad categories encompassing ten themes were induced following the process of thematic analysis described in the methods chapter. The completed analysis of parents' stories included the following thematic categories: stories about other people's assumptions, stories about dealing with difference, stories about professionals and services and, finally, stories about disability. Each category includes a number of themes which are summarized in Table 3.

Stories About Other People's Assumptions	Stories About Dealing with Difference
<p style="text-align: center;"><u>Horrible Pictures</u></p> <p>Examples of parents' stories about initial prognoses from medical professionals and examples of appraisals within the general view.</p> <p style="text-align: center;"><u>Essentializing Stories</u></p> <p>Examples of parents' stories about ways they are stereotyped, labelled and perceived by others.</p>	<p style="text-align: center;"><u>Affective Issues</u></p> <p>Parents' accounts of feelings (grief, guilt and humour) related to coming to terms with their children's disabilities.</p> <p style="text-align: center;"><u>Assessments of "Normal" Parenting</u></p> <p>Examples of parents' stories about parenting in general.</p> <p style="text-align: center;"><u>Making Comparisons</u></p> <p>Examples of various kinds of comparisons parents related they make including: comparisons with non-disabled children, siblings and other children with disabilities.</p>
Stories about Professionals and Services	Stories about Disability
<p style="text-align: center;"><u>Meeting Children's Needs</u></p> <p>Parents' stories about dealing with professionals in various service systems including: early intervention; rehabilitation; school; behaviour management; medical services; and supports for independent living.</p> <p style="text-align: center;"><u>Bureaucracy</u></p> <p>Examples of parents' stories about dealing with the bureaucracy surrounding services for people with disabilities.</p>	<p style="text-align: center;"><u>Larger Discourses</u></p> <p>Examples of parents' historical and sociological accounts about disability and being the parent of a child with disabilities.</p> <p style="text-align: center;"><u>Diagnosis and Labelling</u></p> <p>Examples of parents' stories which speak specifically to the issue of naming and identifying specific kinds of impairment.</p> <p style="text-align: center;"><u>Non Pathological Views</u></p> <p>Examples of statements which represent evolving definitions of disability as being a feature of social discourse and barriers</p>

Table 3 - Summary of Categories and Themes

Stories about Other People's Assumptions

One theme that emerged in the focus groups included parents' stories about other people's evaluations of themselves and their children. This category includes parents' accounts of how medical professionals, as well as the general public, tend to create negative evaluations of their children's conditions. This theme comprises statements which I have called "horrible pictures."

The term “horrible pictures” is derived from one of the parent’s stories, and seems to capture the overall tone of these stories. Parents also related stories about how they are labelled or essentialized. Essentialization refers to culturally determined “dominant specifications for being” (White, 1990; p.50), or to how others have attempted to define the role of being the parent of a child with disabilities based on taken-for-granted assumptions. Thus, “Horrible Pictures” and “Essentializing Stories” are the two themes about other people’s assumptions.

Horrible Pictures

Parents talked about receiving information, usually from medical professionals, about the initial prognosis of their child’s impairment. Many of their examples were negative. One example follows:

I had a pediatrician say to me once oh!, you know, - she painted the most terrible picture. I left; I cried; I was so depressed. She said “oh, they just get so much harder to look after when they reach 12 and they are just so difficult.” I mean, she just went on and on and I left there thinking – good God!, thanks for all the encouragement.

Another parent’s account of receiving a negative prognosis discussed the issue of being given the option to institutionalize her child:

In the beginning, we were given the option to institutionalize her. I don't know if that ever crossed our mind - I mean, it was just one of the things that they laid out there. Even now you think back and you think, my God! What if we had done that? Because they had painted such a horrible picture, that she would lie there like a lump for the rest of her days and she's no way near that. She has progressed, you know, way beyond what they ever predicted.

In the first example, the parent suggested that some kind of encouragement would have been more helpful. In the second example, the parent related that her child's current capabilities contradicted the professional's initial assessment. Another parent in the group added that it was probably because her child was not institutionalized that she had progressed. Neither of the children, in these examples, has reached adolescence yet. With that in mind, the parents related their perception that some professionals in the medical system "had a lot to learn" about some of the realities of living with disabilities. An aside to the second statement is that there are currently no institutions open in the province of British Columbia, so that even if she had wanted to institutionalize her child, this option would have not been available.

The parent in the second example provided the following evaluation of the medical view of disability:

My first introduction to a professional is the geneticist who tells you of your child's disability and nine times out of ten, given the two minutes alone with that person, you would probably kill them because they have never been given any people skills. They deal with genetics, numbers; they are scientists and they can't talk to you - they come right out and tell you whatever and you don't hear anything they say past your child is diagnosed with this... and that's it so then you leave.

While killing the geneticist is a rather violent metaphor, this parent's statement questions the effect of the scientific approach to understanding disability. She would have preferred a more compassionate and communicative approach to finding out about her child's disability. She doesn't want to hear just "this is the condition," and to be left on her own to deal with the implications of her child's disabilities. Other examples about receiving information about a diagnosis, suggested that finding out about a child's disability often involved avoidance on the

part of medical practitioners. Parents reported that when they suspected something was wrong, they were told not to worry. In one case, a parent related that the attending obstetrician left on a skiing holiday with the message that he was having the infant looked at for muscle tone problems. She was informed the next day her child had been diagnosed with Down Syndrome.

In an example of a situation involving the diagnoses of an acquired disability, a parent related the following evaluation which is her interpretation of medical professionals' general attitudes to naming and diagnosing disabling conditions:

A lot of them... they do not recognize that. They also forget to take the caring part... the caring attitude part... "You know what, Mrs Smith I just really am not sure what her problem is but we do care about her." Now, that would have gone a long way. But we often were not given any of the definitions. ...What if we are honest? We don't know and, guess what - we care . Those are kinds of things that would be good to hear a little more often.

The view that people skills were a vital component in professional relationships was echoed in all of the parents' statements in this study. Congruent with this, parents related they were often very able to deal with ambiguity in attempting to understand their child's disability and that a sense of optimism was far more helpful than having definitive answers about what their child could or could not do. The picture these parents painted of doctors having to tell parents about their child's disability was that medical professionals could be overly blunt in their diagnosis of a condition or, conversely, that they avoided the issue. Only two parents related that receiving information about their child's disability was not problematic. In both of these cases the child was not diagnosed at birth.

The medical model was not the only source of horrible pictures for the parents of children

with disabilities. Parents related that other people provided negative evaluations of the situation involving their children. For example:

But I have also had people say to me and I don't know how they could do it (they weren't thinking I guess) but they'd say "oh my gosh! I don't know how you do it, I couldn't handle having a child like that." Well, excuse me! If you had a child like that you'd have to deal with it. I don't know how you'd deal with it!

This kind of experience was common in parents' stories, suggesting people tend to "horribilize" the experience of having a child with a disability. As Sobsey (1995) points out, this practise tends not to support parents' relationships with their children. In this mother's case, it is clearly a source of added frustration.

In similar examples of how parents encountered other people's interpretations of their children, parents were amused, perplexed or simply dismissed unwelcome comments. The parent of a child with marked physical differences related that she simply agreed with people's intrusions into her experience:

The other little boy, his top torso is bigger than the bottom torso so he looks strange when you see him, so they notice right away that there's something wrong with him and they'll go, "My he's a big boy" and I'm thinking, "You don't need to know what's wrong with this fella" and I go, "Yeah he is, he eats lots." So you kind of joke about it to get around it, feeling that it's not really any of their business. Because they are just really being nosey - they're not over concerned about your kid.

This story represents one example of how other people's interpretation of disabling conditions are an intrusion into the lives of parents of disabled children. People are nosey and not interested and,

I think, the parent implies the interest is morbid and not sympathetic. During the early years of their children's lives, a number of parents related the experience of what might be called the subjugating gaze of others. These stories reflect Woodill's (1994) metaphor of a person with a disability as "other."

Another account of other people's general assumptions about being disabled is represented in the following story told by the adoptive parent of a child diagnosed with epilepsy and a brain injury. This example speaks to the prevalence of people's assumptions that to have a child with a disability is a bad thing.

We had one person who unbelievably said, because she knew she was adopted, "are you going to give her back?" I could not believe it! In the Human Resources system they just were used to people changing their minds about children.

The parent, in this example, is disturbed by the suggestion that there are people who do indeed give their children back when there is an indication of disability. She also related that it was something she later had been informed happens frequently in adoptions where children were subsequently found to have an impairment. This parent countered this larger negative narrative about having a child with disabilities with the assertion that she and her husband were "in it for the long haul." Parents' stories about how others viewed their children, in most cases, seemed to suggest that these negative assessments actually strengthened their commitment to their children rather than being a source of stigma. In addition, parents felt supported when other people showed a genuine interest in their children and themselves.

Essentializing Stories

Another way of defining essentialization is as culturally prescribed ideas about the way

certain categories of people are supposed to act. Parents told stories about the ways in which they have been essentialized which include: how disability should affect their lifestyle, parents as advocates, being seen as unable to cope and being seen as a super parent.

How disability should affect lifestyle. One of the parents recounted a story about an encounter with a social worker when her daughter was still in pre-school and involved with early intervention:

Something a social worker told me many years ago, this was when I was still new at CDC and he was actually the best social worker I ever came across (I still have some educating to do with him). But he said to me, "Don't ever let Roberta's disability change your life style." Now, I was crying. I left there crying, thinking, "Okay, I can't ever let this happen." I can just laugh myself right off the chair now to think that how you could have a child with that severe a disability and not have it affect your lifestyle. It's not even a realistic statement. And he was trying to be nice and supportive but, you know, now I know that there is no way.

The parent's account of the experience suggests that, at first, she followed the professional's advice and that this was troubling. Her lived experience contradicted his advice as well as the assumptions behind it. Additional examples from parents' stories about lifestyle issues suggested that their children's disability had often far-reaching effects:

Peter: Everything you do, the house you buy, the car you drive

Mary: You look at the school.

Peter: Where you go on vacation

Debbie: You can't live in certain areas because they have hills.

Peter: Or mud

These examples speak to how professional service systems, by working in isolation, can fail to acknowledge that there are many practical realities associated with living with and accommodating differences. For the parents of children in wheelchairs, in particular, accommodation and access to taken-for-granted aspects of daily living were described as extremely difficult. One couple related that just going on vacation required a tremendous amount of planning and co-ordination, including the need to know what stops they could make, where there were wheelchair accessible washrooms and what kinds of other tourism facilities could be similarly accessed. Their stories strongly suggested that they didn't "just do" anything and that encounters with physical barriers were often physically and emotionally draining. In this respect, the admonition to not let a disability affect lifestyle seems somewhat absurd. These parents evaluated his statement as "totally unrealistic." Given parents' descriptions of the effect of disability on lifestyle, the advice is unrealistic and suggests something more than being misinformed on issues of disability. There seems to be a tacit message in the social worker's statement that disabilities are better accommodated within society than is actually the case.

Parents as advocates. Another version of an essentializing story that parents presented had to do with how they were perceived as parent advocates:

I think that sometimes working with the other professionals there are assumptions..... I guess the angry part that I had was that the professionals put up the barriers and you are the one constantly knocking down the walls.. I think that the labelling you get along with your child, the minute you open your mouth, you may as well pin the label on yourself as well because you are an advocate for your child and lots of services.

In contrast to the previous example, this essentialization represents a double bind for parents. On

the one hand, they are told to not let their children's disabilities affect their lifestyles (which implies that they will need certain kinds of supports and services). On the other hand, if they make too many requests of service systems, they risk being labelled. Parents reported that those labels included "being seen as trouble," "being in denial" and, in one extreme example, as "psychotic." There is a suggestion of a kind of control by certain professionals who de-legitimize the concerns of parents by discrediting their intentions.

Of course, parents mentioned that this is not the case in all instances. One parent related that there were professionals who accepted the fact that their job was to be questioned by parents and another acknowledged that professionals were willing to listen to their concerns. Nonetheless, parents related that they continued to encounter opposition and inaction. One parent saw this as being tied to issues of money:

My experience has been people have asked us, "well what do you want?" We have told them over and over what we want and still we don't have it. We have some of it – they hear it – they ask, but it just doesn't happen. Why? I can only guess. But I figure most of it's got to do with money.

This suggests that the relationship parents have to the larger system is similar to other marginalised individuals who have attempted to articulate the need for social and institutional change. One parent described the issue of getting services as a matter of "constant screaming and yelling" in order to get anything done. Another parent related that the disturbing part of being seen as "trouble" was that government service providers seemed, to her, to be withholding information and that she, as a taxpayer, was paying their salary. In her own words:

It is almost like they are in fear with their jobs, yet their job is to support us. We are hiring them. My tax-paying dollars, you better believe, have them on the

payroll.

Parents, in a number of cases, described an atmosphere of frustration and fear in relation to their attempts at service advocacy. They noted, as well, that there are many parents who have simply given up in the face of this frustration. Their stories suggested that they saw aspects of the bureaucracy which continue to be paternalistic and reactionary. As an example, one of the fathers related that he had to watch what he said to certain individuals for fear of having services cut off.

Being seen as unable to cope. Another version of an essentializing story about parents of children with disabilities spoke of being seen as unable to cope:

So sometimes you are afraid to say that you do need help too. We've heard some of the mothers say that too - if I say that I can't cope they will take my kid away. I'm not asking them to take my kid away. I'm asking for a service that I need or something like that.... The social services, on the one hand, is there to help you but on the other hand, it's the apprehension thing. That never goes out of your mind because you also know well, gee, my kid cries when I give them physio - the neighbours going to call them. And that's happened to a couple of people. Or they fell and they got bruised because they don't walk as well. There's always people looking at you even more closely because of the abuse thing.

The idea that the parent experiences greater scrutiny with regard to abuse suggests that professionals may be working from a deficit model of disability and how it affects parents. More precisely, it is the over-generalization that having a child with a disability always leads to debilitating levels of stress which result in child abuse. The scrutiny is often compounded by certain features of impairment like not being able to walk well. In a similar example, the parent of a child with behavioural difficulties reported that she was offered "counselling" when a rumour

surfaced that her child's behaviour was the result of physical and sexual abuse.

Super parents. Parents' stories about the ways they are essentialized or labelled suggest a subjugating discourse with a somewhat limited set of specifications for being. Being the parent of a child with disabilities, according to these dominant stories, means you can be a plucky survivor of a tragic event trying to live a "normal" life, a strident radical deeply in denial about the true nature of your child or a grief-stricken child abuser. These all seem to be based on tragic constructions of disability. A contrasting essentialization is about the parent who does everything.

One parent related the following:

The general population tells you - you're the parent, you're the advocate. You're the only one that will advocate for your child so you've got the guilt on your forehead so my God!, if I don't do it. You're the continuity, because the professionals change.

The problem is that the professionals may change but the discourse does not. While there is an equal danger in stereotyping professionals, these stories and the examples provided within the theme of horrible pictures suggest that parents of children with disabilities encounter stereotypical views. The parents in this study are attempting to be the best parents they can but, to do so, they necessarily confront the preconceived appraisals by others of what being the parent of a child with disabilities entails. They are not saying it is easy, but it is often made more difficult by these kinds of narrowly defined essentializations.

Stories About Dealing with Difference

One of the central concerns of postmodern social theory is a concern for issues of how the construction of normality becomes a tool for social control. Zimmerman and Dickerson (1996) provide the following definition of normal: "Follows cultural specifications. Fits into dominant

majority. Usually done without thinking. May or may not be appreciated, or enjoyable, or helpful, or anything else.” This category comprises parents’ statements which locate how normal is not appreciated, enjoyable or useful. It also provides examples of parents’ discussions about issues of coming to terms with and creating meaning around issues of difference. Themes include affective issues related to having a child with disabilities, deconstructions of “normal” parenting and the practise of making comparisons.

Affective Issues

This theme included statements parents made about affective issues, specifically, grief and guilt or self blame. This theme also included statements about the use of humour as a coping mechanism. Parents’ statements were particularly interesting in terms of how they intersect with the dominant discourse on normality, both as a source of difficult feelings, and in relation to how there is a normalized way in which the parents of children with disabilities are seen to experience particular types of emotional responses.

Revisiting chronic sorrow. Parents in this study made no mention that they experienced anything other than feelings of sadness upon the birth or diagnosis of their child. The following statement describes one parent’s initial grief following her daughter’s diagnosis:

I can remember thinking when Susan was first diagnosed, you could only look at the calendar two days at a time. You couldn't look at a week. You couldn't look at the future because you would just sit down and cry because you didn't know what the future was going to be because you knew the child had a lot of problems. And so I couldn't even picture her at the age of 15. Whereas you could picture a brand new baby at the age of 15 or going off to college, getting married and all those kinds of things that you couldn't do.

This statement does not challenge the concept of chronic sorrow. The perceived source of sadness, in this case, is in the realization that the child would not lead a normal life. To be sure, sadness, anger and shock were common emotional threads in parents' stories about finding out they had a child with disabilities. There was however, variation in parents' reports about how they dealt with these feelings. In one case, a parent reported that, with the assistance of her mother, she began almost immediately after her child's diagnosis to become involved in an advocacy movement. This contrasted with other parents' statements which suggested they needed time to work through difficult feelings.

Parents related that difficult feelings could resurface. The following story is interesting in that it ties the experience of "chronic grief" to an encounter with a physical barrier.

Now I don't even let myself go there in my mind because... certain times I guess it gets to you and for the chronic grief type of thing it seems to level off, not level off - I can't say that - but I think it sort of isn't as often. You go along for months and not think that your life is any different than anybody else's. You've gotten into your routine, you're doing your thing, everything seems to be going smoothly and then smuck some stupid little thing will frustrate you like somebody blocks you in the parking lot and you can't get your stroller out of the car. I just about had a fit in the parking lot of the supermarket. You know, I wouldn't have this stroller if I didn't have the child with a disability.

For me, this story suggests a different way of conceptualizing chronic sorrow as a feature of society's lack of accommodation. The parent's story in this case relates some hesitancy around whether or not she experiences grief on a regular basis. She experiences feelings of sadness and frustration when she confronts an environmental barrier. This story speaks to the idea that chronic

sorrow is not strictly a problem for the individual. Perhaps grief would be less of a problem for parents if accommodation was more universal. While there are other interpretations to this story, it would be interesting to explore this relationship further.

Parents discussed the issue of acceptance in relation to issues of coming to terms with difficult feelings. The literature review presented examples of research and theoretical approaches where acceptance is seen as an unrealistic expectation. Certainly, this was a cornerstone of the original conception of chronic sorrow. Some of the parents' stories challenged these assumptions. In discussing the issue of coming to terms with the grief of a child's diagnosis, the following dialogue occurred in one of the groups:

Susan: As Julie said, "Will this nightmare ever end?"

Peter: It ceases to be a nightmare. When you accept the fact that's just the way they are. Everybody's different and you have to (and I don't think Julie's anywhere near there yet) - but when you accept the fact that that's the way they are and when you adapt your lifestyle to fit... Either you adapt your lifestyle or you put your kid in respite all the time. Those are the two options and for us, that's not an option.

Mary: People with disabilities have said that too - they don't grieve over that kind of thing.

Susan: She's never walked and then lost it..... that's their life.

This passage reflects a concern that difficult feelings or "the nightmare" have particular kinds of consequences for both parents and children. Peter's story describes a kind of matter-of-fact acceptance and ties it to emotional adaptation. He also makes a relative statement about abnormality - "everybody's different." Mary's comment ties this to the discourse on grief of people with disabilities. This comment is interesting. It is an example which brings up the issue of

how people with disabilities have deconstructed assumptions by others about their lives. This interchange suggests the possibility that these parents have entered into a similar kind of dialogue.

It is significant to note that, in the group where this discussion occurred, there were two parents of younger children. The mother of the youngest child commented, after listening to a related story from the parent of an older child, that she “wanted to get there some day.” By “there,” she referred to a similar kind of acceptance of her child and the ability to look at her situation differently. In another group, the parent of an older child offered the following prescription for making sense of having a child with disabilities:

You have to have this sense of optimism. You always have to keep saying you are doing your best and it's going to get better maybe not tomorrow, maybe not next year. So there's that sense of optimism which is probably why I first spoke about positive things that we experienced rather than negative. Because, you know, I think there is that sense of optimism. Otherwise we would have faltered.

This passage reflects the possibility of a different view of coming to terms with disability, based on hope rather than hopelessness and the disease metaphor implicit in the idea of chronic sorrow. This parent's story suggests that the “cure” for chronic sorrow may well be the encouragement of “chronic” optimism. There is a certain sadness in the notion that many people do not see this as a viable possibility. The previous thematic category documented that the tragic view of disability persists. Parents in this study demonstrate, to a great extent, attempts to redefine a different kind of story. It is one where feelings of sadness are very real but where they occur within a particular social context and where there are useful alternatives to feeling sad all the time.

Coping with feelings of guilt and self blame. Parents related that, in addition to feelings of sadness, guilt played a part in coming to terms with the situation of having a child with disabilities.

As an affective experience, guilt can be seen as an externalized problem which is supported by a number of dominant narratives. This sub-theme includes statements which link guilt to social concerns for pre-natal care, effective parental discipline, and the encouragement of child development. Guilt was discussed in all three of the interviews. These examples suggest that the narrative therapy approach to conceptualizing problems might be useful in dealing with parents' feelings of guilt and self blame.

Pre-natal care and guilt. Parents made a number of statements related to the experience of guilt or self blame. One of the parents shared the following account of her feelings of self blame:

One thing every parent of a child with disabilities experiences this guilt thing, that you go through at some point, when you say "what did I do wrong?" You know it must have been something .. Nobody ever told us it could have... still I was always wracking my brain about what I could have done. Maybe this or maybe that... something like that. You go through this guilt thing. You look at this child and it's not perfect and somehow its my fault. So that's a big hurdle to get over.

This statement was a typical example of a statement made by the parent of a child with disabilities about their own feelings of guilt. It is not a deconstructive statement. It generalizes the issue of guilt to "every parent of a child with disabilities."

Mothers' statements about guilt were generally tied the issue to pre-natal concerns.

Another mother responded to the above statement:

Gee, I thought I was the only one who felt that way. I used to wrack my brain thinking my God!, did I take an aspirin at a certain stage in my pregnancy or something ... what happened here. Because I knew I didn't drink. I didn't drink coffee. I didn't smoke. So I thought I took all the precautions. But you are looking

for reasons.

This statement identifies common health concerns for expectant mothers. In this case however, the mother is the parent of a child with a hereditary genetic condition so that her behaviour during her pregnancy had no bearing on her child's differences. In another focus group, the mother of a child with a genetic condition was eight months pregnant and expecting her second child at the time of the interview. The following dialogue extends the discussion on the relationship of pre-natal care and guilt.

Mary: We have no other child so I would like to have another child to feel okay about me. When I have a child with a disability people look at me like "there's something wrong with her."

June: That label. No wonder, there's something wrong.

Mary: No, I didn't do drugs and no I didn't drink, "but didn't you take folic acid?"

June: Even when it's a genetic disorder, which is a total accident, you still want to prove something to yourself - that you could do it again.

Mary: I was ready a month later. Boy!, I'm going to get pregnant right away.

All three of these statements represent a dialogue about feeling guilty about having given birth to a child with disabilities. None of these mothers provided examples of how they got over the hurdle of feeling guilty except in the third example where the mother was attempting to counter her feelings of guilt by having another child. The issue is framed from the perspective of having to prove herself.

It is also important to note that, in the third example, the parent perceived others were evaluating her for her behaviour during pregnancy. (She did, in fact, take folic acid during her pregnancy). All four of the parents who spoke in these examples reported that they were healthy

during pregnancy, yet the belief that they were responsible for their child's impairment seemed to persist.

These stories suggest that certain perceptions of the information about pre-natal health, from the perspective of mothers of children with congenital impairments, might be characterized as a subjugating discourse. I offer this interpretation tentatively since there is little doubt that the use of alcohol and drugs during pregnancy is a known cause of physical and mental impairment. I am not suggesting that expectant mothers be encouraged to forego good pre-natal care. At the same time, the cultural edict to produce "perfect children" is evident in people's assumptions and this creates a subjugation that mothers of children with disabilities may feel more intensely. What the first parent described as a hurdle, more recently, has become an even bigger hurdle for the parents of children with disabilities because there is the misperception that all congenital conditions of impairment can be prevented through either pre-natal testing or by making healthy choices during pregnancy. Even in the case of alcohol-related impairments, prevention involves looking at more than just the individual responsibility of pregnant women but can also include looking at the larger context of a society where alcohol is the second largest industry next to the production of weapons. As means of overcoming guilt, these parents' discussions suggest that deconstruction might be a useful therapeutic tool. Advising women to have a healthy pregnancy is not the problem. It is the cultural practise of "blaming the mother" because she is perceived to have "failed" that is subjugating.

Guilt and behaviour management. Parents told other stories about feeling guilty related to behavioural issues. In one case, the adoptive mother of a child with an acquired disability related the following:

You know, even for us, and we adopted Karen and she was perfectly normal at

birth. We didn't have the reason for guilt initially. When she turned out hyperactive and they wanted to put her on Ritalin, they looked at Dave and I and said "You know there's one thing missing in your life - you don't have any guilt." She's adopted; I don't have any reason to feel guilty... but eventually they made me feel guilty. (Laughter) You know, we actually assumed the guilt. She started perfectly normal and then it's - "What could we have done"? Then you want to take your normal kids and hold them up and say "See!, we did it right also"... Like what did you do to this child? That was like you are already dealing with the grief that this kid is not going to be the way you had intended this child to be and then somebody comes along and says, "Obviously you are doing something wrong." I mean it's just devastating... I think I mentioned one of our school district psychologists and he wrote a very formal report after doing an in depth study on Karen and the conclusion of his report was - it was a power struggle between mother and daughter. And this caused encoporesis which is soiling of the pants. She soiled every day for 5 years. That was one of the symptoms that we battled and that is a power struggle between mother and daughter.

Earlier descriptions of Karen's disabilities provided information that she does have a significant neurological impairment which is apparent through her behaviour (mood swings, difficulty with school work, etc). The parent, in this case, tied guilt to a particular set of assumptions about the relationship of parenting skills and a child's behaviour. The attempt to construct the reality of her child's behaviour is "devastating" and is informed, again, by an assumption about why certain kinds of behaviour occur. In her case, the assumption is that she has engaged in a power struggle with her daughter.

Another parent of a child diagnosed with ADHD related the following story about her involvement with a local agency:

Jeanette: The only grief I ever had with the [local agency] was that everybody keeps pushing parenting courses at you. If your kid's acting this way, take a parenting course. I've taken them all - the kid figures the stuff out before I do. All they've succeeded in doing is making me feel like an awful parent.

Fiona: Like maybe you're doing something wrong.

Jeanette: Yeah, if that kid acts this way, you're doing something wrong. Could it just be, you know, that my kid acts this way.

This story represents a similar set of issues to the first example and was echoed in a number of the parents' statements about difficulties with children's behaviour. Parents provided examples of behaviour which clearly represented practical problems: screaming, temper tantrums, and aggressive behaviour towards others. Admonitions about how to discipline from both professionals and friends or family contributed to guilty feelings. For example:

Carol: It is not because they meant any harm by some of their advice. They just didn't know.

Helen: We always used to get - Well, if you just give her a good lickin'

Carol: She's spoiled rotten

Mary: See you guys are all helping me because we have kind of been through that and I think hmm, you know - is that legit.

A parent of an older child brought up the point that understanding their child's difficult behaviour without feeling guilty involved coming to a form of acceptance that there were no definitive answers for changing behaviours.

Because they even admitted that they are not sure in this field of behavioral management or whatever it is but they don't know all the answers. There's always new stuff coming out and, as somebody said, everybody's different so just because the prescription is for this person, it is not the same for that. You can't box people up and I guess that's avoidance of putting labels on. It kind of helps you generalize the condition but it's not the same for everybody.

This parent's retrospective analysis of behavioural prescriptions suggests that a reasonable and pragmatic approach to dealing with problem behaviours is preferable. In other examples, parents related that this was often not the case and the belief in definitive solutions often led to feeling guilty for not having done the right thing, the right way at the right time. In other words parents were "made to feel guilty." From a constructivist perspective, the dominant story is that children's difficult behaviour is the result of a failure of parents. There is an added level of difficulty in that much of the children's behaviour is tied to a feature of their impairment. Children behave differently because they have specific and often idiosyncratic neurological differences.

Guilt and developmental concerns. In addition to discussing behaviour management issues, parents related a number of concerns about their children meeting developmental milestones. As another example of how parents develop feelings of guilt, one of the parents expressed guilt over the issue of when to toilet train her daughter.

Sandra: ...but part of me, like Debbie was saying, I have to give her the most I can and feel comfortable with it and if she can be potty trained and that's a step forward for her, then I have to have her potty trained, but how do I know? When is the little light going to go on, or this whole thing that shows when she's ready, like that it says in the normal kids' books, like it says that they show signs that they

are ready.

Debbie: That's your problem - you're reading those bloody books!

From Debbie's perspective, the "bloody books" are the problem or more precisely it is the dominant story on developmental milestones like toilet training. To be sure, the mother of a child with learning disabilities in another group related that she felt that her son was "behind" because he wasn't toilet trained until he was three. One parent suggested that being toilet trained is a "fetish for professionals." It is a fetish of the culture to standardize stages and that fetish can lead to feelings of guilt. There is a wide range of ages when children adopt particular learned behaviours, but the assumption about the right age to toilet train appears to be somewhere around two. For parents of children with disabilities, it becomes another layer of discrimination. To emphasize the point, one of the parents related this story about taking her non-disabled son to pre-school:

Regular kids in pre-school have to be trained. In other cultures they're not. My son was 3 when he entered pre-school and I said to her is it okay if I send him in a diaper, he's more or less potty trained but rather than have an accident.... She goes, "Well, I don't know, we've never had one." And I turned to my husband and said "oh my god!, we're the first parent who took a kid to pre-school when he's still in a diaper"(Laughter).....and then you have a kid with a disability and its like, yeah, you just got kicked twice.

Parents' stories about toilet training and remaining in diapers emphasize that developmental issues are often problematic for parents of children with disabilities. One of the ways they deal with this kind of subtle subjugation is to question the assumptions behind it . The "bloody books" is a metaphor for the overly generalized view of developmental psychology. This

is similar to the overly generalized view of appropriate behaviour.

Humour. Parents related that humour was often an important way of coping with and making sense of their situations. The discussion about toilet training, in the previous example, included a great deal of laughter. In all three groups, parents shared humorous stories. That parents laugh at their situations, suggests an antidote to the tragic conception of disability. The following statement presents one parent's analysis of humour:

I think humour is very important. We use a lot of humour at our house. It's a little sick sometimes but it's gotten us through a lot of times when it was either laugh or cry and you just can't cry any more so you know you joke about it and you deal with it and you move on because you can't make any change.

Humour clearly can be seen to be a matter of perspective. The spouse of the parent in the preceding example shared that (s)he had joked with his/her daughter, who is in a wheelchair, about walking outside to feed the dog. It is not difficult to imagine people being offended by this kind of statement particularly if they have adopted a tragic view of disability. In this respect, it would be seen as "sick." From the perspective of these parents, it is quite normal and helpful.

Parents' statements about humour suggest that it need not be a subject with which to be overly cautious. The following exchange describes parents' first experience in joining the support group.

June: I think people are sometimes surprised when they first come to the group and I don't know if Mary can speak to this but people here will always hear Parent Support Group. We don't spend a lot of time weeping and whining. I mean, yeah, there is a little bit of frustration every now and then but really our desire is to share information.

Mary: I was looking for weeping and whining.

(Laughter)

Debbie: So was I and there was none - not even five minutes. I thought we were supposed to have a glass of wine, all break down and get this out and nothing.

They made rude comments and smart remarks.

(Laughter)

Mary: I thought, "Who are these people?"

Karen: But you kept coming. You persevered.

Humour, from a deconstructivist perspective, involves laughing at assumptions about what is supposed to be the correct response to a given situation. This dialogue fits this definition. Instead of weeping and whining, the parents of younger children not only received useful information, but also had the chance to laugh. Certainly, for individuals steeped in the pathological view of disability, the laughter is difficult to appreciate.

Assessments of "Normal" Parenting

Parents' stories about being a parent also challenged assumptions about parenting in general. The example of toilet training in the previous theme is one example. The following story is another:

That's what you do with your other kids - you sort of ignore them.... You have to say too, okay if you're tired and you want to sleep in on Saturday morning, so what. I taught my kids a VCR and TV - there's the button, go to it, because I'm not getting up in the morning..... You want to watch a show And I'm lucky that she can do that.....

While the effect of too much television is also the subject of a critical debate, this statement is a

positive example of a parent not succumbing to the discourse of trying to be a perfect parent. Parenting, whether a child is disabled or not, is stressful and it is unrealistic to expect that the parents of children with disabilities should be held up to a higher standard.

The idea that parents of children who are different deconstruct so-called normal parenting is intriguing. To be sure, around issues of discipline and behaviour management, parents constructed a different set of rules for their children with disabilities because they understood behaviour in terms of the child's impairment and were better able to identify assumptions about 'accepted' child rearing practises. There was also a suggestion in many of their statements that this had also softened their attachment to more traditional forms of discipline with their children without disabilities. The process of stepping outside what is considered normal and seeing how it is socially constructed is a central tenant of postmodern theory. Parents' evaluations of general principles of parenting suggest that, in having children with significant differences, they tended to gain new perceptions and meanings about what it means to be a parent. One parent referred to the process as having the opportunity to learn things about herself and others that she would not have had if she was not the parent of a child with disabilities.

Making Comparisons.

The practise of making comparisons was discussed in all three of the focus groups. Parents related stories about comparisons of their children with disabilities with normal children, including siblings. Parents also talked about comparisons with other children with disabilities. Their stories provided examples where comparisons were not useful as well as examples of where making comparisons had a beneficial effect.

The first example of a statement made by a parent about the practise of comparing represents a personal declaration about the problem of making comparisons. In this case, the

parent is the parent of a young child:

I won't do that. I will not do that! You know, so what! This is what I have. I don't care. I don't want to compare. I have stopped going on the Internet because all I would do was compare - forget it, I don't want to do that anymore. I don't want to compare.

This statement was very emphatic. Making comparisons is a problem for her. She wants to stop comparing. She says "this is what I have." This statement suggests a view of making comparisons which is congruent with the constructivist process of externalization. The problem is not, in this case, the child. It is the practise of making comparisons between her child and other children, both disabled and not.

This passage is an excellent introduction to the theme of comparisons. This theme encompasses two sub-themes: comparisons of children with disabilities to "normal" children and comparisons with other children with disabilities. In this section, and in keeping with the use the language of narrative therapy, I refer to the problem of comparisons. Parents' ways of talking about comparisons with normal children suggest a congruence with the idea from narrative therapy that people have relationships to problems rather than problems being within people. This is not meant to deny that there are other possible interpretations of parents' statements about comparisons (e.g., cognitive behavioral therapies; Nixon & Singer, 1993). Instead, I present this as a potential example of how comparisons might fit within a narrative therapy framework.

Comparisons of children with disabilities to normal children. One parent related her perception of the problem of comparisons which described them as inescapable or constant:

My niece has a daughter who was born 2 days before mine so they are exactly the same. We get together in the summer and her daughter is running and playing and

going to school and she's Miss Lady with her hair and everything and my daughter was still crawling and lying on the floor, so it's a constant reminder.

This passage constructs the problem of comparing her niece's daughter to her own as one of being a "constant reminder." This is an undeconstructed view which defines a particular relationship to the problem of comparisons. They are troublesome.

Another parent related the following example of coming to terms with the problem of comparisons through a process of reframing his perceptions of his daughter. From a narrative therapy perspective, this process can be described as changing his relationship to the problem of comparisons.

It still took a while to get over that, especially with my niece being 2 months and a day difference. It is bad enough when you have an older child who hasn't been through the same stuff but they are not side by side at the same age and it takes a while You come to realize that Roberta is different but that's not all bad. We have met people we would not have met otherwise. We know that, although she has a disability, that her disability has led to some good things. We went to session at the school here a couple of weeks ago MAPS² and one thing that I mentioned, that the [fundraising event] in this city is a direct result of Roberta's disability.

There's been \$100,000.00 raised from the [local agency] and it would never have been raised if it weren't for Roberta's disability.

In this case, the parent relates that he has come to see that there are benefits to having a child with disabilities. There is a difficulty when a child is close to the same age as another child the same

² A MAPS session is an instrumental planning tool used in special education to facilitate the development of social relationships between disabled and non-disabled individuals.

age but, in time, the parent changes his relationship to the problem of comparisons. This story also elaborates the issue of how more positive appraisals from the community contribute to a lessening of the need to compare children with disabilities with "normal" children. This parent's description of the process suggests it helped him clarify and reframe his perceptions of his daughter in more positive and relative terms.

One parent related an example of a comparison of a child with disabilities to his/her non-disabled sibling. This example suggests that comparisons, in some cases, can lead to a more positive evaluation of a child with disabilities.

And all of a sudden through adolescence and there's all kind of imbalance in our normal child. I think we were spared from some of that so far. And with Nancy we are seeing some of those same things and thinking that maybe Sally wasn't so bad. Maybe a normal kid can give us a lot more grief than you do.

These kind of statements were made in reference to the fears parents experienced around adolescent children. Parents did not have to worry about their children with disabilities experimenting with drugs or going through phases of rebellion. In two cases, parents made statements that they enjoyed the aspect of being able to be involved with nurturing their children with disabilities longer than their more typical children. These kinds of stories fit within White's (1990) therapeutic framework of looking for unique outcomes - where problems (i.e. comparing) are no longer problems. In the two parent support groups, these kinds of conversations appeared to be a part of the group's existing dynamic. Parents of younger children would tell stories about the issue of making comparisons and older parents would present examples of unique or different outcomes. This suggests that the therapeutic aspect of parent support groups can be similar to narrative approaches to counselling.

Comparisons with other children with disabilities. Parents' stories about making comparisons of their children with disabilities with other children with disabilities suggest issues relevant to critical cross-disability perspectives. The following story brings up the issue of parents' comparisons of their children with other children with disabilities:

The first time I went to the [local agency], there was another family there and the family has two children with severe disabilities. And one of the days when I thought I couldn't do anymore I just thought, I have one, she has two, I have one she has two - I can do this, I can do this. Then years later, I found out that I have a girlfriend, who I've known my whole life, who has a son the same age as Keith, 14, and he has some minor learning disabilities and stuff and she would just say "my kids only got minor learning disabilities, look at Debbie." I was using somebody else to make myself feel better.

During her early experience of coming to terms with her child's disabilities, this parent used comparisons positively as a cognitive coping strategy. She does, however, look at this strategy from both sides and question the usefulness of comparing impairments hierarchically according to severity or type. In the following example, a parent provides a similar analysis in her statement about a friend whose child has a learning disability:

My girlfriend has a child with a very minor disability but the frustration in the education system is just getting to her, and she always says to me, "And I know you've got it worse, but my problem is important to me." And I think, "yeah, you're absolutely right. It doesn't matter what the disability is."

One of the critical definitions of disability is that it is a feature of society's lack of accommodation for people with specific kinds of differences or functional impairments. The parent, in this case,

suggests that a perceived hierarchy of severity tends to be particularly problematic for people with so-called mild disabilities. The parents of children with learning disabilities in other focus groups shared these same concerns in stating that a huge hurdle for them was in trying to get people to recognize that their children required accommodation for their impairments. In one of the cases, where a child was diagnosed with ADHD, the child had also been tested in the gifted range. Since his hyperactivity was pronounced and problematic, several recommendations were made by psychologists through Children's Hospital, which the parent had varying degrees of success in meeting. Her major concern was that certain types of disability appeared, to her, to be favoured within service systems. These parents' discussions suggest a subjugating and divisive discourse on disability framed according to severity. The central issue in cross-disability perspectives is about accommodation, regardless of the type or severity of impairment. There are different accommodations for different impairments and, certainly, some impairments are more severe than others but accommodation seems to be equally unavailable and difficult for people regardless of their specific impairment. It can be argued that this reality is masked by language practices which create an evaluative hierarchy of severity. From an advocacy perspective, this discussion needs to be extended.

To conclude this theme, parents' discussions about the problem of comparisons include the dimensions of comparing their children to non-disabled children, children with other types of disabilities as well as children with the same type of disability. These parents' stories about making comparisons show that comparing is something they do not take for granted.

Stories about Professionals and Services

A salient feature of parents' narratives had to do with their relationships with professionals and professional service systems. In most cases professional supports are seen as

essential and parents have developed positive relationships with the professionals in their lives. In other instances, parents expressed considerable frustration at impersonal, bureaucratic and treatment-oriented systems and the professionals they viewed as integral to them. Parents were particularly critical in their assessment of the medical model.

These parents made positive appraisals of professional relationships when professionals gave parents choices, when they demonstrated a genuine concern for their children and themselves and when they were honest about what they knew and did not know. Negative appraisals referred to being made to feel blamed, feeling left out of their children's lives and decisions affecting them, receiving overly sympathetic or overly negative evaluations of their children and their lives and being prescribed specific treatment or intervention agendas that were difficult to manage in the context of their day to day experience.

The category of stories about professionals and services comprises two themes. The first, meeting the child's needs, is a large theme which is divided into the various kinds of interventions with children. These include: early intervention and rehabilitation, education, behaviour management, and medical treatment. The second theme comprises parents' statements about dealing with bureaucracy. Within both themes, there are a number of issues relevant to critical perspectives on disability. These issues include parent and professional power relationships, the practical validity of certain types of interventions and consistency in the application of service principles.

Following a description of parents' stories, I also present some commentary. In presenting stories about parents' relationships with professionals, I have selected some negative examples. My intent in selecting parents' examples of problems with professionals is not to cast helping professionals as villains. It is, rather, to define and elaborate these relationships from a critical

perspective. To that end, the analysis offers some suggestions about why stories about parents and professionals seem to revolve around adversarial themes.

Meeting the Child's Needs

Parents of children with disabilities dealt with a number of systems providing specific interventions for their children. In most cases, this required a great deal of time and energy and constituted one of the key differences between themselves and the parents of children without disabilities. On the surface, many of the parents' statements might be construed as criticism, particularly because they cannot be countered by those working in the various systems. The intent of presenting these themes is not intended as a denigration of particular professions; rather, it demonstrates that certain narratives within those systems continue to be based on assumptions about disability which create additional problems for parents and their children. In other words, it is the stories and not the people that I am subjecting to critical scrutiny.

Early intervention and rehabilitation. Nearly all of the parents in this study had or continue to have relationships with early-intervention professionals involving various kinds of therapeutic or rehabilitation relationships, including, occupational therapy (OT), physiotherapy (PT), speech pathology and infant development. The first example of a parent's statement about early intervention describes the issue of having a number of professionals come into her child's life.

Once you have a child with a disability, it's almost like it's not your child, it belongs to the system. Like, I already had a child and nobody came into my life. I had this child, and within 3 months, I had probably visits from 4 different professions - the health unit, child development centre, infant development on and on and on. You know, everybody coming to pay you visits and not only at the Child Development

Centre. You had speech therapy, physiotherapy, occupational therapy. I had never had so many people in my life at one time and you felt like this child did not belong to you.

This parent's evaluation of these services does not refer to the quality of services but to quantity. More importantly, it suggests that the degree to which there is intervention with a newborn impacts the parent's ability to develop a relationship with the child. "It belongs to the system." To be sure, parents related that most early intervention and rehabilitation professionals have the best of intentions in assisting parents of young children with disabilities. Parents made several positive statements about early intervention and the professionals who supported them during this period. In one case, a parent was thankful that professionals "took over" during the difficult times of coming to terms with her child's diagnosis. Parents' stories about early intervention, however, talked about the need to sort out appropriate balances between developing a sense of acceptance for their child and getting their child's needs met. Parents' stories described what seemed to be an army of professionals coming into their lives, immediately and quickly. The parent of a two-year old reported coming home from the hospital, with her daughter, and having to go to several appointments right away:

Well so happens, we get back and I'm thinking go home and everything will be normal (thinking in my head, it will be normal probably thinking she'll be normal). Get home and the first week we had, in five days, seven appointments. Well, it would take me an hour and a half to bathe her, get myself ready and get there. I did this all by myself because my husband wasn't home. So you realize quickly, she is not normal.

I do not present this story to be interpreted as insensitivity on the part of early intervention

professionals. Parents also related that funding issues played a role in the extent to which various therapies were available. One parent described the situation as “having 6.11 years to get everything done.” My experience with early intervention professionals suggests they work under this kind of pressure plus the added pressure that the funding they get is never enough. However this mother’s story suggests that one of the results of existing arrangements may be subjugating for the parents of newborn children in particular.

In another example of a discussion on early intervention, parents discussed issues related to what I described in the literature review as the fixing narrative. The following statement describes one parent’s assessment of the rehabilitation discourse:

Everybody is in Roberta’s life are there to do good, speech, OT, PT. They want to fix Roberta but Roberta isn't really broken. Roberta is just Roberta and you know, yes, we can make her a little better, she might be able to do things a little better but that's simply Roberta. And once we got to the point that that is Roberta and she doesn't talk and she doesn't walk but that smile says everything.

This statement questions the assumptions that people with disabilities are deficient or “broken” as a result of their impairments. On a certain level, it challenges the professional discourse on rehabilitation. This kind of statement is perhaps provocative and contentious for rehabilitation professionals who, undoubtedly, “are there to do good.” These efforts are, nonetheless, constructed by this parent as attempts to fix her child. The same parent related her perception of a trade-off between various kinds of therapy and what she felt to be more important issues for her daughter:

We've sort of come to the understanding that speech, OT, PT - all that's on a consultative basis. If it was not an integrated classroom, she would probably be in

a segregated school getting services to meet all those needs and probably would be developmentally further ahead but the trade-off is she goes to birthday parties, she has friends come to the house. Everybody in that school knows her. It is quite a small school. She is accepted, probably more than people would ever imagine and our hope is that when she is finished school some of those friendships will carry on and would they have happened in the normal situation in a segregated school?

The further context to this statement is that the parent, during her child's preschool years, had worked very hard to get as much rehabilitation and therapy as possible. I do not think her use of the term fixing is intended as a denigration of various therapies. I think it speaks more to a shift in emphasis from one agenda (rehabilitation) to another (integration and inclusion).

In another instance a parent described his appraisal of rehabilitation in the following way:

What is it that we're trying to accomplish? On the one hand they'll all tell you you have to have time for yourself and at the same time they are telling you if you don't do this physio they are going to get contractions or you have to work on drool control. Okay, when do we fit that in.

To me, these stories speak to the need of finding balances and an understanding of context. Therapy is important but it is only one element in a person's life. From my experience in special education, I know that it is often extremely difficult to co-ordinate things like drool control or other forms of therapy. In addition to this, there is the reality that the recipient of therapy is often not very interested in engaging in the practise, particularly in integrated settings where, from their perspective, there are much more interesting activities. When children with severe disabilities were segregated, it was easier to set a therapeutic agenda. In my experience working in a hospital school program, therapy times were routined, sometimes bordering on

regimental. Perhaps, the subjugation here lies within systemic structures where professionals are working in isolation both in the settings where they work and in the disciplines in which they are trained.

School. Parents' statements about the school system reflected a range of concerns, including inclusion, appropriate educational supports and relationships with school personnel. The issue that emerges in these statements is inconsistency. On the whole, parents related that school could be a pleasant experience and a source of support but that it could also be a source of added stress. Many of the parents of school-aged children said that teachers had spent considerable time with their children. Parents felt that teachers and teaching assistants appreciated and knew their children better than other types of professionals. Their stories suggested however, that finding appropriate educational supports for their children was often a "hit and miss proposition."

The following anecdote presents an example of how inconsistency created a problem for a parent and her children. This parent found that, within the same school district, approaches to the accomodation of children with disabilities varied a great deal from school to school:

How I got around it in the school system was when I moved. We recently purchased our own home at [neighbourhood]. And when I put my kids in [school], I didn't bother telling them anything about them. I just said, "this is Sarah blah, blah, blah. She's in kindergarten and this is her brother." And I thought - I'm not going to let them know that they have problems because they are going to automatically pre-judge them, think that they can't do as well or (be) behaviour problems and they are going to ride them and that kind of big deal. It kind of backfired on me because at [school] they had supports. I should have told them ahead of time.

This parent related that her decision to not disclose her child's disability was the result of a previous experience at a different school where she felt that her children were unnecessarily prejudged by school staff and where she was constantly called to pick one of them up. In the school district where this parent lived, inclusive education at neighbourhood schools is a district-wide policy. According to her perception, the application of the philosophy is not consistent.

One parent also related that within schools, people's understanding and support of inclusive education varied a great deal:

We found that we were the first to go into the school system with inclusion and that was quite the shock to everybody you know.... We are into our eighth year and still there are people who have been in a relatively small school who still have these assumptions about you and your child that I just find unbelievable. Don't you talk in the coffee room? Haven't you heard how things are going?

Other parents' stories about school suggested that positive experiences with their children in school hinged on school staffs' positive and proactive view of disability. Some of their stories suggested that the more traditional and standardized the approach to teaching, the more difficult the situation could be for them. One of the parents of a child with learning disabilities related her experience with a teacher who she perceived as unable to make a shift in her thinking about suitable education for her son:

I don't think it (consultation and education about her son's learning difficulties) would have worked with his kindergarten teacher. Stuff like trace the 1 in five different colours, 73 different times and then she couldn't understand why he was bouncing all over the room. (my parentheses).

In other cases, parents identified problems with school that had to do with overly low

expectations and the relegation of teaching duties to teacher aides:

The worst thing is the professional, particularly the teacher, who doesn't have any expectations. Cause you run into those. We had a teacher like that two years ago who basically abdicated all responsibility for Roberta's education to the aide.

These parents' expectations for special education, whether it was in integrated settings or not, suggested they still run into negative appraisals from some teachers about their children.

Parents who described positive experiences with the school indicated that they were impressed by individuals who went out of their way to provide extra support for their children. In one case, a parent related that she felt professionals might be frustrated with their own overly high expectations:

I think one of the things that's got to be really frustrating for any of the professionals that work with our kids, though, is that we do, like you say, come to some sort of acceptance that you know that some things aren't going to happen. We're all so really happy with the small little things and they can be really tiny little things but it's progress and it's very hard for the professionals. I think they maybe see themselves as failures. Especially if you are a teacher for one year or something and she's got expectations of that child and that child doesn't meet them but the kids learn this much but the teacher had this much. You know, it took me years to come to that acceptance so how can a teacher or somebody?

The broader context to this statement reflects a concern for how education has come to be seen as a system which does not necessarily value "little things." This parent's story also appears to contradict a stereotype about parents of severely disabled children as having unrealistic expectations for their children. The parent in this particular case, defined acceptance as "being

able to learn some things because” she believed “learning never stops.”

Parents’ positive evaluations of the public education system typically referred to developing active partnerships with school personnel based on open communication. Parents of school age children and parents of adult children who had finished school all shared that they had had at least one positive experience with their children’s teachers. Parents’ appraisals of the school system were generally more positive than their appraisals of other service systems.

Behaviour management. Behaviour management issues were discussed by eight of the parents (six families) whose children were seen to have behavioural problems associated with their disabilities. Parents expressed criticisms of particular approaches to behaviour management and discussed the idea of professional certainty.

The following statement is a general challenge to assumptions of certainty of behavioural interventions:

I think the problems are very much more complex. Maybe these problems always really were more complex and there wasn’t the research that went into the roots of the problem. How is a professional person supposed to know everybody’s little intricacies from the little problem that might have set this child off, or what was it?

Behavioural problems are complex and are not remediated by a single solution or set of interventions. Individuals have intricacies and interact within a complex set of environments with different individuals. Parents related that they did, however, run into professionals’ attempts to provide either quick fixes or essentialized explanations.

Parents saw some of the quick fixes as ethically dubious. The parent of a child diagnosed with autism related that (s)he was instructed to pull her/his daughter’s hair whenever she started to scream. Another parent pointed to what she termed:

A take a pill mentality... It's like if they don't know what to do then they will try this and see if this works and they have no idea if it's going to work or not anyway so your kid is turned into a guinea pig.

In both these cases, the parents related that the interventions aggravated the behavior and had the net effect of causing them greater levels of stress, confusion and guilt. In the hair pulling example, the child eventually started to pull her own hair out. One parent related that a different kind of problem arose because she perceived that professionals refused to believe that her reports about her son's behaviour were real because he was "so cute." Clearly, parents related a considerable amount of frustration with issues around behaviour management.

In some parents' perspectives, behavioural prescriptions seemed to be offered with little consideration of the consequences, not just for the child, but for the parent as well. Parents felt that professionals who offered these prescriptions often seemed to do so without an appreciation of real-life context. The parent of an older child who had behavioural difficulties when she was younger related a retrospective analysis of her experience in receiving behaviour management advise:

Why don't you take the number of behaviour management plans they have in their file box? I could be up there. (laughter) Some of them I've read; I was going through some today and I actually laughed out loud at a couple of them and I thought, What!, they actually did this. I know I didn't. I mean, I couldn't follow their advice on some of these.

Parents appreciated advice on behaviour management when it was given with understanding and a lack of certainty. The parent in the preceding example was particularly critical of "gimmicky" or contrived interventions. Another parent related that she felt that

behavioural advisors were often not holistic, suggesting that she felt behaviour problems were looked at as pathologies or diseases with an implied "cure."

A parent of a child with autism related that (s)he came to see behavioural problems as an opportunity to learn something:

And of course, we have to move forward and in moving forward you make some errors or maybe errors in judgment or whatever. It is really not errors. It's a trial, I guess. Some of it's trials and other ones are errors. I think that we felt that we always moved ahead. It has always moved ahead one more notch. Sometimes back one step, moving ahead two but it was always a gradual moving ahead to achieving a balance and so, and then it helped us at times when it was really difficult to cope with certain situations. Some situations occur and you just don't know what to do. People are all looking at you. What are you going to do about this? You know. So these were kind of like tools given to us and of course it wasn't really appropriate in every case, but what do you do? You gotta try it out. I think we found other ways to achieve that same result, you know, and we just had to figure that out.

This parent's approach to achieving a balance around issues of behaviour management suggests a questioning of the certainty of behaviour modification. This parent's evaluation of behaviour management is not about finding a single solution based on behaviour modification principles. Rather, it is about a slow evolution of pragmatic trials of learning from mistakes and achieving a balance. That the parent hesitates in calling these interventions "trials" or "errors" is interesting as it suggests being caught between two perspectives. Autism, from a more critical perspective, is not a behaviour problem to manage; it is an impairment to accommodate. This parent's statement

about having "to figure it out" questions the long term efficacy and the underlying assumptions of certain types of behaviour management principles. It is also interesting to note that, again, the gaze of others plays a role in which interventions are chosen. Perhaps in people's desire to help parents with issues of behaviour management, the issue of the influence of how others perceive those behaviours is often missed. People do look at and judge the behaviour of people with autism but, really, whose problem is that? Deconstruction of the parent's relationship to the problem of people's subjugating gazes, in this case, might be an entirely appropriate and less stressful intervention. Certainly, it is better than pulling the daughter's hair.

Clearly, psychological knowledge cannot be stereotyped as a set of rigid generalizations. One parent did, however, share a story about a situation which suggested an encounter with a professional who over-generalized a particular principle.

We had one experience in [provincial hospital] and a psychologist was asking us all of these hundreds of questions... One of the questions was, "Do you have pets in the home" and we said, "Yes" and she said, "Is Kelly ever rough with the animals?" I said, "Yes, sometimes she's a bit rough," and on to the next question. Well, then we get the formal report – "this child displays cruelty to animals." (Laughter) And I remember saying, "This isn't my daughter, she likes them so much. She hugs them hard or she makes them dance." But it was interpreted by this gal... I just... It was sort of funny ... it wasn't going anywhere. But the thing was, that it was in her file, so somebody, if this report was going to be passed onto somebody else or somebody caring for this girl... You know, it would influence how she may be perceived and even had problems with certain behaviours that were really extreme. The really super extreme behaviours are really infrequent but, because there are

reports somewhere, there have been certain people who haven't felt comfortable about caring for her in a day-program or-house-sitting with her for an evening when her caregiver's away, or whatever. Because they see these violent aggressive incidents which is so infrequent and usually provoked by some mismanagement. That they can be explained away quite easily if you talk to me, but because it is in a report then it's there for anyone to interpret how they want.

The mother shared that this interview with the psychologist took place at the same time that there was considerable media coverage of research into the relationship between psychopathic behaviour in childhood and cruelty to animals. Her story is an example of the effect of out-of-context professional appraisals parents might encounter. Further to this, her example also reflects a concern for what these kinds of appraisals can mean in the construction of the social identity of a child with disabilities. They can have serious consequences. The written word, particularly the word written by a professional "teller of truth", has authority. At best, in this case, uninformed care-givers would keep the child away from animals. At worst, it is troubling to think the child could be labeled as psychopathic.

Medical Interventions. Parents' stories about their interactions with the medical community were introduced in the section on horrible pictures. Parents made a number of other statements about doctors and other medical professionals which reflected different kinds of issues. Parents of children whose impairments were not apparent at birth made statements about the way some doctors minimized their concern about their child's apparent differences or lack of ability. For example:

Well my first experience was not a good one because we had noticed with our daughter that there was developmental delay. She was a second child and we were

very suspicious at, say, 7 months old. She wasn't sitting up like she should have been and then by the time she was a year she wasn't walking and I'd had her back and forth to my family doctor and he said, "Oh well, Don't be too concerned; some kids are just lazy" and so fine.

This kind of minimization was noted by other parents in similar situations. Professionals' reluctance to identify a difference can be interpreted as a variation of the negative evaluation of disability. It might reflect an implicit assumption by some professionals that naming an impairment is something to be avoided unless absolutely necessary. In fairness to doctors, the communication and pursuit of a diagnosis means they may have to be the bearer of bad news. Furthermore, diagnosis, in some cases, is difficult, time-consuming and can be expensive. I do, however, think that because traditional medical models emphasize the pathological and negative aspects of impairment, a part of some doctor's reluctance to name a condition of impairment may be rooted in these negative connotations.

In some cases, the reluctance to diagnose can lead to serious consequences. The following parent describes an example of such a situation:

Like, I struggled tremendously with the medical profession because it was mainly medical people that we saw, although it was psychologists and psychotherapists and it was psychiatrists as well as neurologists - everybody. Everybody said, "Oh, she's fine, keep her home, love her." She wasn't capable of doing the things at age 10 that she was at age 5. When she was finally diagnosed and they finally put her on medication - in her particular case it was epilepsy and at that point the epilepsy had done irreparable brain damage and the medication was going to prevent more from happening but not to repair what was already lost and I have to say my

frustrations with the medical profession were definitely there by a mile.

One of the parents, in a different group, related similar frustrations with the medical system citing both economics and politics as reasons why she felt there were problems. Clearly, current health care funding is seen to be in crisis and parents' criticisms should be seen in light of a system under strain. The above example, nonetheless, speaks to the idea that there is a tendency of some medical professionals to be dismissive of parents' concerns about impairment. The fact that the end result of the dismissiveness, in this case, was more brain damage leads to questions about the narratives that inform how doctors deal with issues of parents' perceptions of potential impairment. A part of this narrative probably relates to the fact that many parents' fears prove to be unfounded. On the other hand, perhaps if doctors were more aware of the possibilities rather than the limitations of living with an impairment, it might mean they would be less reluctant to pursue a diagnosis. Again, in fairness to doctors, I think there is also a tendency of some parents to miss the wider issues related to the diagnosis of impairments and to blame doctors when their expectations that doctors know everything are not met.

Another issue the parent discussed in relation to the medical profession had to do with having his/her child being seen as an experiment:

And I mean, they just went like this (rubbing hands together) when they saw... because she was so rare. Its like, "We've only ever had three cases of this in Canada but now we have one in Vancouver." It was wonderful, right? ...Also, the idea that you are an experiment, or they're experimenting on your child, bothered me a lot. These drugs are not proven in any way, shape or form, but we're going to try them on your kid. You know that when it's a tried and true drug they charge you for it, right. So you know when your child is on experimental drugs .

This parent related her perception that it was interesting that after the difficulty of putting the label on the child, the medical establishment then embraced the condition and looked at the child as a chance to study the condition and to experiment with drug therapies. One of the critiques of the medical model, from a critical perspective, is that it objectifies people with disabilities as human anomalies for the purpose of study. While there is a subjugating stereotype of doctors as disinterested clinicians or “pill pushers”, these kinds of stories suggest that, at least, issues of openness and respect are features of the intersection of parents’ and doctors’ narratives. The same parent in this example related earlier that (s)he would have appreciated doctor’s honesty about not knowing her/his child’s diagnosis if medical professionals shown more of a “caring attitude.”

I should point out that I am not a medical professional and comment with caution on many aspects of the medical model and medical practise. To situate my analysis, I probably share many of these parents’ biases about doctors. In my professional experience, I have had similar encounters with doctors. In one instance when I was working at a hospital for children with multiple impairments, I was interrupted by a group of paediatric interns and their instructor. The instructor proceeded to lecture his students without asking me if he could interrupt what we were doing and positioned his students directly between myself and the student. When he finished, he left with no apology. One of his students returned a moment later and offered an apology. I would hope that most doctors were more like the student in this case and less like the teacher.

In defence of professionals. In selecting statements to present in this section, I have presented some of parents’ negative evaluations of professionals and professional service systems. This was not intended as a denigration of professionals who work with children and adults labelled with disabilities. Undoubtedly, many professionals in disability-related fields are in the forefront of advocating for the rights of individuals. My intent in presenting parents’ “horror

stories” is to elaborate how more dynamic definitions of disability create the need to critically examine subjugating cultural practises. Some of the parents spoke about the value of developing partnerships with professionals. They also spoke about challenging what I would call “expertness” as opposed to expertise. These parents welcomed expertise and saw it as essential. Expertness refers to the social distancing created when professionals claim or are seen to have definitive answers and present those answers to parents in such a way that the parent perceives their own interests to be inferior. Partnerships are based on equality and mutual respect not on imbalances of power.

Again, it has been my experience that many professionals understand this fundamental professional value. In understanding the parents’ point of view, however, perhaps not enough emphasis is put on viewing parents of children with disabilities as members of a socially marginalized group. Historically, parents of children labelled with disabilities have been oppressed by many of the same kind of sympathetic and pathologizing assumptions as have individuals with disabilities. Like other oppressed groups, a certain “in-your-face” attitude in their criticisms is to be expected. Unfortunately, I think, professionals often get caught in the middle of this larger struggle and may be seen as the enemy regardless of how they act with parents.

Another element in defence of professionals is the influence of the systems in which they work. Services for people with disabilities are severely underfunded, often staffed with individuals with little training in disability-related issues and often are provided in an atmosphere of ambivalence. In other words, professionals face their own version of the culturally subjugating discourse on disability. In many respects, it is understandable how professionals who work under these conditions succumb to the temptation of easy answers or to hiding behind the mantle of “expert.” In my own experience, I, too, have been frustrated. Usually, my frustration revolves

around the addition of one more bureaucratic requirement. With that in mind, the analysis proceeds to the theme of parents' stories about bureaucracy.

Bureaucracy

In all of the interviews, parents related that dealing with certain kinds of service systems and professionals could be a source of stress. They had little to say that was positive about bureaucratic aspects of the system. Parents told a number of stories about how they have received the "run-around." The following story is long but it was told with a particular clarity and humour.

I had a social worker one time who told me that I could no longer have my cheque come to the house; it had to be deposited directly to my account. And she told me that it had to be so. So fine, I signed the papers and everything and then I spoke to another parent who said, "I've just been told that it can no longer be deposited directly to my account; I have to have the cheque come to my house." I said, "But that's the way I wanted it." I phoned her back - I said, "Disregard that; I want the cheque just to come to my house....." You know, she phones me back and says, "Now June, we can't have this. It is policy." And I'm thinking, "No it's not." "You have two policies there and one is going that way and one is going that way - I want to be on that."... You know, I'm trying to be light about it and everything. This is in the middle of my day when I'm not having a good day anyways. She just keeps going on and on 'til I'm so tired I go with my phone and I sit down at the table and I'm saying, "listen to me, this is a simple thing. Don't make my life crazy. All I want is the cheque to come to my house, okay." And she goes, "But no" and I'm going... And eventually I've got my head down on the table, and I'm going "Don't make me crazy; listen to me. This is a simple thing. Do what I'm asking; call

me back” and I hang up the phone. I can't believe this. Honest to God, she phones me back after making me crazy for probably half an hour and says, “Oh June, that's quite all right; you can still have the cheque come to your house.” I phoned my husband and said, “Never! - I never want to deal with this woman again.” (Comment from another parent: “She probably heard you were having a good day and said let's mess this up”).

Parents told a number of these kinds of stories, and for all three of the groups, trouble with professionals and service systems was included in their list of prioritized issues. Their suggestions for dealing with bureaucracy, in some cases, bordered on the idea that the best thing to do with it was to just eliminate it. Even in cases where parents had tried to cooperate with bureaucrats, they still expressed the concern that they felt as if these professionals were hiding something. In one case a parent related that he actually experienced fear in relation to particular individuals working in the system.

The fact that the parents told so many of these kinds of stories, however, leads to questions about why parents (or professionals or anybody) continually face these kinds of stressful experiences. While some parents told stories about positive experiences with the system, parents also reported that they felt as if ministry personnel were hiding information and that they felt they were perceived to be “trouble” if they asked too many questions or made too many requests. Parents also felt that they had opened up their lives to the ministry for close scrutiny and that there was little reciprocation. Taken as a whole, the stories parents told about negative experiences with bureaucracy suggests the persistence of power imbalances which cannot be simply dismissed as paranoia. What parents described seems to represent a particular kind of ideology at work within these larger systems. These parents' stories strongly suggest a need to

know what that ideology represents. From the perspective of these parents bureaucracy is a key aspect of Lenny's (1993) "disabling society."

Stories about Disability

This thematic category brings together parents' stories about disability. This category represents a collection of parents' stories which are specifically relevant to the critical definition of disability. This category includes the following three themes: Issues related to larger historical and sociological discourses on disability and being different, parents' stories about diagnosis and labeling and parents' stories which elaborate non-pathological views of disability and being the parent of a child with disabilities. This category concludes a section discussing my observations on what parents did not deconstruct.

Larger Discourses

Statements collected under this theme represent parents' attempts to make sense of the issue of disability from a historical and sociological perspective and relate to parents' philosophical and ideological outlooks. They demonstrate that attention to the bigger picture plays a key role in how they have made sense of their situations.

Historical discourses. One of the parents in the study presented the following capsulized history on being different in society:

We went – like the generation of older kids – the ones that are adults now...went through a time of transition as far as the experts in the field were concerned because there really are sort of two roles you know. You are either a normal person being part of the normal society or, if you didn't fit there, then there was institutions.there was still those two spots that people could be – either you are in or you are out. And anybody else that should have been in that was out, kind of

walked the streets – that’s the street people. They were categorized. I think people were already put in these slots. Nowadays, it is way different than the institutions. These institutions, the traditional ones, are gone and so the thinking has really changed a lot, especially among professionals. And I think that they are a lot more sensitive to recognizing the differences in people with developmental difficulties and I guess they put labels on people; I mean more labels have been developed than were used at that time but I think they are avoiding even labeling people now because everybody has potential and hopefully that’s the positive approach that the professionals are using – that everybody has possibilities and they should be encouraged to develop to the potential, whatever that potential is – you don’t measure people according to somebody else but according to their own individual potential. I think the philosophy has changed an awful lot.

This passage is presented in its entirety because it points out a number of issues related to meaning-making. This parent’s construction of the evolution of services for people with disabilities is powerful in its conclusion that “everybody has possibilities.” That statement is a key aspect of the deconstructed view of disability. That there appears to be a contradiction about whether or not there are more labels being put on people is interesting. The latest version of the *Diagnostical and Statistical Manual (DSM-IV)* (1994) would suggest that labels have proliferated. On the other hand, he is stating that he sees a more widespread critical evaluation of labeling than in the past where the essential reality implicit in the label was widely taken-for-granted. Historically, the confusion about labels in his statement is entirely accurate. Current debate over coming up with more and more diagnostic categories is indeed contentious and confusing. A critical and somewhat facetious view has emerged which says anybody who wants to have a

disability can have one because the DSM-IV categorizes everyone (Davis, 1997).

Another parent's construction of historical evolution of services ties the issue of inclusion of children with disabilities to the work of parent advocates. In this story, parents are seen as the chief agents of social change.

All the progress in services for disabilities has all come from the family. It has not come from the professionals because if families don't push, it never changes. The first time we heard him (Lou Brown³) speak was in Richmond and he gave a capsulized history of special education in the States which is probably very similar to in Canada and how it started... Before World War 2, it really wasn't an issue because there wasn't a big population of people like that. The baby boom hit after WW2. He went through the whole thing. Parents would come and say "I have a child with Down syndrome. Can he come to school?" "No, we don't deal with that go down the street." And eventually this parent would say, "No," so they say, "We will set up a special school" and eventually a parent comes through the door and says "No, they go to regular school" - "okay, we set up a special classroom." Eventually the parent comes through the door and says "No, we go to a regular classroom."

This parent's spouse later pointed out that receiving this kind of information played a key role in helping them reframe perceptions about their daughter.

I really think it (acceptance) came with going to listen to Lou Brown the first time.

I had no concept - I didn't ever see her going to school. I mean she wasn't yet two

³ These parents related that Lou Brown is a frequent speaker at a provincial parent-advocacy conventions.

and I'm already worried about school and down the road. And when I listened to him... I knew she was going to school and this is what we were going to do and this is what I expect and then I came back with all these expectations and you could see these therapists going - "Who told her this stuff!?"

Parents also related that a good deal of their understanding of disability issues revolved around concerns growing out of their knowledge of institutionalization and segregation. For example:

I guess I am really interested in the deinstitutionalization of the adult. You know, when they came and they started living in group homes and stuff and they are getting more and more support and they are also getting educated for themselves. I am waiting to hear what they are going to say about their life and what they want because I think that one of the good things that will come out is that they will say - "No, I want to be able to do this and I have choices here." And you know, they'll add to the community as they learn about living outside. I mean they didn't have... when I think of the institutions, I mean, as a student nurse, I went over to mental health, huge health hospitals. When I think of it now, the power the ordinary person had and the workers had over these people. It was phenomenal. And the basic things that these people didn't have.

Parents in this study clearly believed that disability is a human rights issue. In contrast to stories about people working from medical, tragic or bureaucratic models of disability, their critical analyses provided a much more positive basis for making sense of their situations. It is also important to note that parents' reality is sometimes at odds with more deficit-based conceptualizations of disability. The report that the therapists asked "who told her this stuff?"

suggests that this is a struggle which is far from complete.

Sociological Discourse. In addition to offering a historical analysis on disability issues, parents also expressed a concern for sociological issues. These statements were of interest because they suggested a concern for much broader social issues than just disability:

Actually it's our society, this North American society, nowhere else in the world that look to outsiders to care for our disabled population. You know, most societies it's the family, the village, you know, they all look after those people. Is that idealistic? I mean that's what I see.

This parent's statement suggests a desire for a greater sense of community, which implies that the problem is not necessarily impairment per se, but the social structures and the ways in which they define and respond to those impairments. North American culture revolves around the nuclear family, individualism and independence. Having a child with a significant impairment requires the assistance of extended family and the community, and, as one parent related in the following example, requires interdependence rather than independence:

At the word independent, I guess I go ballistic. Don't tell me to teach my kids to be independent because nobody is ever independent. We are all dependent on each other and the more we deal with that, rather than the independence thing and have her take off her coat. I don't really care whether she takes off her coat. It just exhausts her and she can't learn anything else. So trying to balance those kinds of things and trying to say, no, I want her to know as many people as possible because she is going to have to depend on any number of people rather than just 2 or 3. If you isolate her in a segregated school or in a segregated room you are effectively telling her she is dependent on 3 people. I want her dependent on 30

people in a regular classroom - 30 kids, who are going to be working with her, hiring her, whatever, looking after her as a caregiver.

In the debate on inclusion, these kinds of assertions are often missed. Advocates for people with disabilities, like this parent, are not saying society should just create more humane conditions for people with disabilities. They are saying that society needs to redefine some fundamental and taken-for-granted aspects of existing social relations. This would include cultural pre-occupations with independence.

Parents in one of the groups in Lakeville expressed the view that living in a smaller community was significant factor in their adjustment to having a child with disabilities, particularly in relation to the factors mentioned above.

I mean there were lots of very difficult times. But I think that we were fortunate in being able to be in a small town like Lakeville that had a lot of support, not just the professionals and those that were interested, but from the community at large.

That really made a difference.

To summarize, parents' statements about community and interdependence seem to reflect not just a new awareness of disability, they speak to a renegotiated set of cultural practises. Their statements are congruent with the idea that it takes a village to raise a child.

Making Sense of Labels and Diagnosis

Parents discussed the issue of specific diagnoses or labels in all three of the interviews. This theme emerged in the analysis in regard to constructivist concerns for the practise of naming or constructing realities of particular kinds of differences. In this regard, I found that many of the parents' statements about the specific diagnoses of their children were seen not congruent with critical constructivist theory. Parents tended to describe their children's various diagnoses as real,

rather than as socially constructed.

A number of parents communicated that a specific diagnosis did not create problems for them but that it helped them in accessing services. For example:

You don't want your child to have a label but my child has a definite diagnosis and I think it's easier in the system when your child is labeled because you know exactly - although there's many variables with the label and my child has fallen through the cracks a couple of times - but it is definitely easier, if your child is labeled.

For another parent the issue of diagnosis related to meeting a child's specific educational needs:

We did not know until Bonnie was 17, what the problem was and all we ever got was developmental delay due to unknown cause but had we known, we would have had more to go with for education and different tactics to use... had the labeling happened at school age, say 5 and 6 years of age. There's certain characteristics that I've read about since I've known what her diagnosis is that just fits her perfectly and there are behavioural management ways of dealing with people.

Both of these statements represent the view that having a specific diagnosis is useful. There is a practical utility to having a diagnosis and problems are seen to be created by not having them.

For both these parents, their children's diagnoses are well documented and defined genetic conditions with fairly apparent physiological and neurological characteristics. Both parents related that information they have about the condition fits exactly or perfectly with the experience of their child. The first parent does however note the possibility of falling through the cracks and describes the value of the label as a systemic need.

Within some parents' statements about labeling is the distinction between the stigma associated with the labeling of a condition and the identification of the individual functional differences. One parent spoke about a doctor's reluctance to get a full diagnosis for her child:

And her doctor said to me, "You know Mary, I really don't like having labels on kids" but I said, "We have to have the labels to get the funding otherwise she's going to be left to fend on her own at school and that's not fair." And then he agreed to send her up to Dr. Jones to get it done; otherwise he wouldn't have - he said, "I don't like labels on kids." I said "it's not really a label on her it's a label for the school system so she can get funding." He said "Okay, as long as that's the only reason you're doing it." Well what else would I do it for? I already know that she has problems.

This parent describes the specific diagnosis as a systemic need. The school needs a label in order to give her child services. The parent is confronted by the doctor's dislike of labeling kids. In this example, the parent deconstructs the doctor's view of labeling. His view seems to suggest the assumption that having a label will result in stigma for the child. This may be a genuine concern but, within the existing configuration of public schools, children can only get assistance in school if their problems have names. Sadly, if the child was left to fend for herself, then she might get all kinds of other labels like "lazy" and "unmotivated." The situation this mother relates is truly inescapable. Returning to the first example presented in this theme, having a specific label is indeed what "makes it easier within the system."

Parents also discussed the more critical aspects of labeling which had to do with perceptions that their children would be "pigeon-holed", not allowed to "express their complete potential," "held back" and "written off." For parents, the issue of labeling was more important

for how it related to their own day-to-day experience with their children. Certainly, they related they were concerned with the evaluative aspects of labels, but for the most part their statements reflected an acceptance of a reality underlying the label. Particular aspects of Down Syndrome, Fragile X, ADHD and the various other named disabilities were seen to fit with their experience. It wasn't the name of the condition that created the problem; it was the way those conditions were perceived by others. Other people's perceptions seemed, in some cases, to be that these names were imbued with a power to stigmatize individuals. For many of the parents, stigma was a secondary concern to having a general framework for understanding how their children were different and for accessing appropriate services.

The Big Picture - Non Pathological Views

This theme collected parents' general statements about their experiences in raising a child with disabilities. In many cases these statements were the initial responses of parents after being asked to describe their experiences in raising a child labelled with disabilities. They are presented as a summary of many issues in previous categories.

The parents in this study described their experiences as living in a different world from that of parents of children without disabilities. That world is sometimes sad, and sometimes frustrating, but it is also a world of rewards and challenges. The first parent to speak in the first interview described her family's experience:

We had lots of support by close family, friends and in the education system, the school system. We have had some problems with the kind of supports we want through social services, but if we look at the whole total picture, I would say that they are small problems that are gone. They are not large problems. I feel there are ways to work through them and we have worked through a lot. People that I

have met through having our child... have been wonderful people and there have been a few that have really helped a lot in the big picture. Generally, they have been wonderful people. We have gained a lot of knowledge ourselves. We had pretty positive experiences. But everything isn't perfect and we're all still working for things.

This is not a problem-saturated tragic description of the experience of having a child with disabilities. There are problems, but there is a way to work through them. There is the suggestion that various service systems played a role in providing supports and that in the end the acquisition of knowledge and the development of relationships are some of the rewards of being the parent of a child with disabilities. The parent in this case is the mother of a young adult with developmental disabilities. In contrast to this, the following statement is from the parent of a younger child:

There isn't a day goes by that I don't look at her as child with [name of syndrome] as opposed to my daughter. She still can make me laugh and we still have lots of good times and she is still my baby even though she is 5 and a half, and that's been good for me too. I mean most mothers love that part of it and think... I don't know that I'll ever just see her as a child - not with the disability. Yeah, I'm fitting into the same role as these guys in that my life is ruled by the calendar....we had counselling in the beginning and that was okay. That was nice to go and talk to somebody. Again it's part of just having somebody listen is the biggest part. And some of the professionals look like they are paid to listen and others really care.

This statement suggests some ambivalence but it, also, is not tragic. It suggests more of an attempt to make sense of her situation by balancing the benefits with the problems. While parents' general descriptions of their experiences varied a great deal, they all suggested that having a child

with disabilities was a different experience. Emphasis should be placed on “different.” Having a child with an impairment is not a bad thing, for all parents, in every situation, at all times. It has rewards as well as problems. Parents’ stories in this study appear to confirm this position.

Parents’ stories however, also speak to other issues. These parents’ stories suggest that they have adopted (or are in the process of adopting) an individual view of parenting and what it means to live with a disability. To a great extent, my sense is that they want to be able to tell their own stories rather than to live according to accepted versions of what it is supposed to be like to be the parent of a child labelled with disabilities. To be sure, I found some of their stories contained contradictions and inconsistencies. From a constructivist perspective, this is a good thing because, unlike knowledge based on a single or essential truth, individual narratives are neither logical nor straightforward.

For these parents, being able to tell their own stories is an important feature of coming to terms with having a child labelled with disabilities. There are, however, other important issues. I argue that the culture does not make this easy for them since parents interact in a world where many others may subscribe to disempowering views of disability. Parents told a number of stories about how service systems and disabling narratives created problems for them. The following example is a description of this type of result and also is a strong example of a deconstructed view:

I used to have people say, “I don't know how you cope,” (I couldn't cope) and, you know, I really think that it's not Roberta that is the problem. It's the hoops that I have to jump through the rest of the time and that's the problem. The child is not the problem. It is what I have to do to go through the steps to get the service I need for my child. That is the most stressful, most aggravating thing I think any

parent comes across.

In this parent's story, the bigger problem (the "hoops") is tied to the system and rooted in the dominant discourse on disability. It is not the child, it is not the nature of the impairment and it is not, strictly speaking, the parent's cognitive appraisal of her particular situation. This statement is very similar to both, the idea that the problem is not the problem (Watzlawick et.al., 1974) and the critical definition of disability where disability is a problem of the disabling society (Lenny, 1993). This parent's perspective suggests that counselling strategies based on more critically oriented principles such as deconstruction are potentially useful. She has deconstructed a particular view of disability and is in the process of constructing another. This same parent began the interview by stating "knowledge is power." I did not ask her whether she had read Foucault.

The parents of children with disabilities in this study related their experience with stress sorrow and frustration. They talked about how particular kinds of support can help them reframe their assumptions about their children, give them an outlet for venting emotions and give them specific strategies for dealing with stressful situations. Many of the parents' stories suggested, however, that larger themes are also important. In listening to and analysing these parents' stories, I found that some of the parents' comments contained a powerful depth of perspective. In attempting to learn about and develop effective strategies for living with difference, these parents have developed philosophical insights which challenge stereotypical views of being the parent of a child with disabilities as well as specific aspects of both social service delivery and the dominant social narrative.

Observations on What Parents Did not Deconstruct

In conducting this research, I have tried to stay open to examples of what parents have not deconstructed and viewpoints which do not fit within the framework of critical perspectives on

disability. The analysis of parents' stories about labeling and diagnosis provided some examples where parents may take for granted the constructed meaning of labels of impairments. Parents stories about affective issues suggested the view that "every parent" of a child with disabilities experiences certain difficult feelings. In the theme of comparisons, some parents described the reminder that their children were not normal as constant and difficult. In this respect, I would describe many of these parents' stories as intersecting more traditional perspectives and the emergent view that to have an impairment is not a bad thing. The critical perspective of individuals with impairments, presented in the literature review, suggested that individuals with disabilities are seeking a dialogue on parenting and disability based on an acceptance of differences which does not equate disability with sickness and death. For some parents of children with disabilities, I think this perspective may take time.

Perhaps the most candid revelation a parent made was a reflection on other parents of children with disabilities whose children had died.

I think that one of the other things was, two families that we knew did have deaths and it is for the rest of us kind of hard too because you do still think... "how would we feel if that was our kid." In a way, there is sort of a feeling. Well they're out of it now. They don't have to deal with this anymore. It is going to take them a while to adjust but they're going to leave our group and go on and do different things and there is sort of a bit of envy there, you know. They can now revert to a normal life. On the other hand, there is the fear that it could happen to your kid too and how you would deal with it.

While a critical bias about acceptance is that it is preferable, this parent's story is an excellent reminder that acceptance cannot be forced. While I think this parent's story is about ambivalence

rather than sorrow, it is nonetheless a testament to the fact that for many parents of children with disabilities, the old stories still resonate.

Summary

These results have detailed parents' stories about the following: other people's assumptions about themselves and their children; coming to terms with difference affectively and cognitively; relationships with professionals and how elements of professional discourse can create problems for them; and parents' constructions of disability and impairment.

In talking about other people's assumptions, parents related stories which I have called horrible pictures and essentializations. Parents provided examples which suggest that they have identified these as subjugating discourses or, in their own words, assumptions. The purpose of creating this theme was to elaborate the various kinds of stereotypes about children with disabilities and their parents. Their stories demonstrate that tragic and dysfunctional views of impairment persist. The important point from this theme is that this often contradicts parents' lived experience. Parents also related that they also encountered narrow views of themselves. They perceived they could be seen as stoic survivors, in denial, unrealistic in their expectations, more prone to abuse their children and finally as the champions of advocacy. Some of these stereotypes contradicted each other.

In their stories about coming to terms with difference, parents talked about the emotional issues in coming to terms with their child's impairment. Many of their stories did not deconstruct the assumptions about feelings of sadness and guilt detailed in the literature on counselling of parents of children with disabilities. In other words, those feelings were very real for parents. Their stories did demonstrate that feelings of guilt and sadness can often be compounded by features of cultural discourse. These features included a lack of accommodation for their

children's differences, a discourse that blames mothers for producing less than perfect children or parents for not toilet training their children by the age of two and what I would say is a discourse that is conceptually similar to Oliver's (1993) idea of the "fetish for normality." Comparing for these parents was something they did not take for granted. Humour and optimism were seen to be antidotes for sadness and guilt.

The themes and sub-themes in the category of stories about professionals sought to locate parents' perceptions about the various different kinds of professionals and systems they encounter. Many of these stories were negative. Parents talked about too much service, too soon (early intervention), service given with no appreciation of context (behaviour management and rehabilitation) not enough service (medical systems), service that varied within the system (school), service they perceived as objectifying their children (medical systems and rehabilitation) and service which just did not make sense (bureaucracy). I presented their assessments of service as attempts to redress imbalances of power between themselves and professionals. Their stories suggest the importance of developing partnerships. They deconstructed what I have termed "expertness" rather than specific expertise.

The final category was parents' stories about disability. Parents' stories about disability included their own historical and sociological analyses of what it means to be different within the existing culture. They provided examples which situated their stories within an historical framework and which spoke to an idealism about diversity that suggested that problems of disability are a feature of existing social structures. Parents talked about the need for labels and how it made it easier in the system if their children had a specific diagnosis. This was not seen to be deconstructive. On the other hand parents also talked about how assumptions about diagnosis could create problems for their children. Finally, some general descriptions of parents'

experiences, detailed the deconstruction of the tragic narrative on disability.

CHAPTER 5

DISCUSSION

Analysis of the Results

The hypothesis of this study was that the stories of parents of children labelled with disabilities about their own process of adaptation, growth and coping deconstructed the dominant discourse on disability and its effect on parents. Returning to White's (1991) definition of deconstruction as "procedures that subvert taken-for-granted realities and practises", the narratives of parents in this study provided a number of examples of statements which identify taken-for-granted assumptions about disability, about being the parent of a child with disabilities and about the complex set of social and professional relationships in which the parents of children with disabilities interact. Parents' stories also provided examples of statements which support the critical discourse on disability where disability is not a problem for the individual but is a problem of the disabling society (Lenny, 1993). To be sure, not all of the parents' stories fit within these critical frameworks. A summary of the results of these focus group interviews with respect to the three research questions follows.

Question 1. To what extent have parents of children with disabilities deconstructed dominant social discourses about being the parent of a child with disabilities?

If the dominant social discourse on being the parent of a child with disabilities is understood as the predominance of a tragic or pathological view of parents, then much of what these parents said did not fit with the conceptualization that parents are "suffering from chronic sorrow" or inordinate amounts of stress. This is not to say that parents did not experience difficulties related to feelings of sadness and guilt, nor that stress was not a reality of their day-to-day lives. These feelings however, were not the sum of their experience. They were also

concerned with issues of making sense of disability, were involved in advocating for their children and related stories about rewards as well as difficulties. Their individual perspectives varied with respect to the aspects of their experiences they emphasized and how they had changed their relationships to the problems and challenges associated with raising a child with an impairment. If there was one commonality to these parents' stories, it revolved around being able to tell their stories and to have those stories validated. While I have not presented an analysis of the theme of supports, parents related that they thought that there was a tremendous value in parent support groups. This value related to an empathy that was sometimes unavailable through either friends, professionals or other family members.

Laughter, for many of these parents, was just as important as were tears. Those tears were not, in all cases, a pre-programmed emotional response to having produced a "defective" child, but were often tied to society's lack of accommodation of their child's differences and to others' unexamined beliefs based on the dominant story of the value of being "normal." The example of experiencing chronic sorrow in the parking lot when someone had blocked the handicapped access is important because sadness about having given birth to a child with disabilities needs to be viewed against the backdrop of society's chronic lack of acceptance and accommodation of individuals with disabilities.

Feelings of sadness were also tied to the idea of normal. From a critical constructivist perspective, normal can be viewed as an example of a subjugating language practise. It is exacerbated by the practise of comparing. The example of the parent's refusal to compare suggests a need to have control over this subjugation and implies a rejection of the "fetish for normality." Zimmerman and Dickerson (1996) present an interpretation of narrative therapy where problems are personified as entities. The title of their book is "The Problem Speaks." and

throughout their writing and their therapy they use a narrative device where the “problem” literally speaks. The problem of comparing speaks frequently to parents of children with disabilities and much of what it has to say is not very helpful.

Parents made statements which challenged particular aspects of the professional discourse on disability. They talked about the need to question professional certainty. They did not question expertise, however, and they welcomed advice when it was useful. They did question the certainty of “expertness,” particularly the idea that there was a single solution to every problem. Parents expressed a desire for professionals to broaden their view of the context of their lives. Many kinds of interventions were seen by parents to be neither practical nor useful. It is significant that at least one of the parents expressed the view that her daughter was “not broken.” Going to birthday parties, having friends, being independent (and interdependent) and safe were far more pressing and important concerns for her daughter than strict therapeutic agendas or complicated behaviour management plans. It is a cliché, but my interpretation of what these parents wanted most was for their children to be happy.

These parents also discussed historical and sociological aspects of disability. This suggests that having access to this kind of discourse was an important part of how they have made sense of their situations. Their interpretations of these discourses suggested a commitment to the move away from segregation and institutionalization and towards the value of greater inclusion and tolerance. Parents also suggested that this change continues to face cultural and systemic barriers. I find it disturbing that some of the parents reported that the movement towards inclusion is denigrated by some professionals and that these parents interpreted this as professional fears about a loss of control.

Some of the parents’ statements suggested that they are involved in a kind of

revolutionary dialogue. In one of the groups, a parent mentioned that 500 people showed up to a government- sponsored parent advocacy convention. The sponsoring ministry was surprised at the turnout. They had expected fewer. The father added that a deputy minister was quickly sent up to address the concerns of those parents. Based on this parent's observation, it is accurate to say that there may well be a growing movement of politically informed parents in this province with a very different kind of consciousness about disability.

On the subject of diagnosis and labeling, some parents related stories which do not necessarily represent a deconstructed perspective. From a critical perspective, to say that information about a particular kind of disability "fits exactly" is problematic because it suggests that there is one "true" way of characterizing a particular impairment. On the other hand, one of the criticisms of constructivism is that it can lead to a questioning of everything, or that it becomes what Olssen (1996) describes as nominalism. Given that the focus of this study has been the use of critical constructivism as a social thesis, it is important to emphasize that parents also shared stories about how labels are limiting often because of other people's assumptions of what those labels mean. Parents described their children's conditions of difference in specific behavioural terms or as having particular kinds of problems. As a pragmatic concern, this points to the need for constructivists to be careful in rejecting all claims to legitimate knowledge based on empirical observation. Neurological, physiological and genetic differences, regardless of how well they are understood or socially constructed by scientists, represent observable phenomena with various commonalities and very real implications for day-to-day living. From a critical perspective, it is when reductionist views supersede an individual's identity that they become problematic.

Question 2. With regard to counselling and support, do these parents' stories identify

assumptions made by help-givers based on dominant constructions of disability. Do these assumptions impact negatively on the counselling and support they receive?

Parents presented examples of how others tend to essentialize their experience. The example of the social worker advising the parent to not let disability affect her lifestyle represents a profound lack of understanding of living with disability. Together with other forms of essentialization, the dominant story is based on assumed pathology. Parents reported that, when they became politically active, they risked being labelled as being "in denial" or as being seen as "trouble." One parent also suggested an emergent conception of the "super-parent" of a child with disabilities, where advocacy is placed solely on their shoulders. Shapiro (1993) describes an analogous polemic for people with disabilities in the conception of "Tiny Tims" - the sympathetic image of the disabled poster child - and "Super Crips" the remarkable individual performing super human feats (e.g. Terry Fox).

Parents also discussed ways in which their children were evaluated based on other people's' assumptions about disability. The theme of "horrible picture" detailed what I would suggest is the persistence of out-dated stereotypes about disability. One of the parents was offered the choice of institutionalization. Another was asked if she wanted to give her child back. Parents related that people assumed that their children caused them more stress and grief than was the reality. While parents also told stories about individuals who held more positive views of disability, they related that many people continue to base their assumptions about their children on negative and tragic views. One of the parents commented that she hoped that people at least try to learn something more positive about their children. Unfortunately, these parents' stories suggest that there continue to be some people who do not. I think her wish suggests ambivalence more than it does discrimination. In this respect, parents' stories foreground the continuing need for

education and awareness of disability issues particularly in light of inclusionary service philosophies. Many of these parents negative experiences with professionals were in service areas where personnel had no specific training in issues of disability and impairment.

Question 3. What are the particular kinds of problems which form the content of parents' need for counselling?

One of the original purposes of these interviews was to generate data about what parents viewed as most important in relation to the content of counselling and support. In conducting the interviews, the intended procedure for generating this data was applied inconsistently between each of the groups. In the Lakeville support group, the final part of the interview involved a formal elicitation of parents' priorities by having each parent describe what were the two most important issues to them with regard to counselling and support. The top three issues were derived by looking at which issues got the most votes. In the Mill Town support group, because of time constraints, I addressed the issue quickly by asking participants to agree or disagree with what I thought were the most important issues. In the Lakeville CDC group the prioritization of issues was accomplished by having each of the three parents pick the most important issue for her personally.

In retrospect, the consensus-ranking component of the study was problematic because of the nature of open-ended focus group research. Each of the groups had a distinct group dynamic. In the case of the pre-existing support groups, parents were very comfortable talking with each other. In the Mill Town support group, in particular, parents enjoyed sharing their stories. While this produced rich data, it meant that it was more difficult to impose the kind of structure necessary to accomplish the process of prioritization.

With the above mentioned points in mind, Table 4 summarizes each group's ranking of the

top three issues:

Group 1 LVSG	<ol style="list-style-type: none"> 1. Accessing supports for child's independent living 2. Frustrations with Bureaucracy 3. Behaviour management Issues
Group 2 MTSG	<ol style="list-style-type: none"> 1. Parent - professional relationships 2. Day to day coping and management 3. Making connections with other parents of children with disabilities
Group 3 LVCDC	<ol style="list-style-type: none"> 1. Frustrations with medical systems 2. Getting support for children's needs 3. Other people's expectations <p>(these are not prioritized because each of the three participants picked one.)</p>

Table 4 - Summary of the ranking of issues.

Foregoing the procedural inconsistencies for achieving these results, they do point, in all three cases to a concern for involvement with professional service providers as an area of concern for counselling. The overall content for all three of the interviews generated more statements and stories about professionals and service systems than any other topic of discussion. Whether this was due to the nature of focus groups (these conversations are relatively safe), or whether that is truly how these parents perceive their needs for counselling, is difficult to determine. Parents in the Mill Town support group made mention of the fact that the presence of professionals and the need to access services was a central concern of their day-to-day lives. Similarly, the parents in the Lakeville groups told many stories about their involvement with other professionals. While this specific question has been answered haphazardly, when these results are taken together with the analysis presented for the first two questions, these parents' stories suggest that it is important for counsellors to take an ecologically oriented perspective. In other words, counselling parents of children with disabilities involves looking at more than just affective issues. It also involves looking at both ontological and systemic issues. This is congruent with Berry's (1995) use of social ecology as a tool for counselling parents of children with disabilities.

Question 4. Are the constructivist theoretical principles of narrative therapy relevant and useful in the practise of counselling parents of children with disabilities?

This study has explored constructivist counselling theory and dynamic definitions of disability in relation to the counselling and support of parents of children with disabilities. It has presented information from the narratives of three groups of parents of children with disabilities that show examples of how these theoretical perspectives might be useful to counsellors and other support people. While I have co-constructed the presentation of parents' stories, it is important to point out that some of the specific statements that were seen to be deconstructive (i.e. - the child is not the problem) were unsolicited. In this respect, the constructivist counselling idea that problems are not within people is potentially very relevant to working with the parents of children labelled with disabilities.

I would argue that the two other elements in these parents' stories also suggest that narrative therapy is a relevant and useful approach. First, parents situated their narratives within a historical and sociological framework which explicitly examined cultural assumptions and wider meanings about disability. Second, parents identified and questioned assumptions or essentializations about themselves and their children. Many of these assumptions were subjugating attempts to construct their social realities which were implicitly and explicitly offered by professionals. Deconstruction, in this regard, involves helping parents to unmask the "truth" of subjugating stories by providing alternate evidence or stories which contradict those assumptions. Deconstruction also involves validating parents' thoughts and feelings in regard to their family's experiences as long as this is done without a violation of the child's rights or needs.

Another strength of narrative approaches to therapy with regard to parents of children with disabilities is that it is an approach to therapy which has somewhat consciously divorced

itself from the medical model of psycho-therapy (Zimmerman & Dickerson, 1996). Parents of children with disabilities often spend a lot of time with medical people who (necessarily at times) focus on the pathological aspects of impairment. I think the emphasis on stories is a useful alternative to being involved in clinical and sometimes impersonal medical settings. "Disabilities is not measles" (Rioux, 1994, p.1) has emerged as a kind of slogan in the field of disability studies. Narrative therapy works from a similar sensibility about counselling. Narrative therapists do not treat people for their problems; they listen to their stories.

In keeping with Peavy's (1993) notion that no single counselling approach can be used in all counselling situations, some cautions are in order. These parents are not representative of all parents of children with disabilities. They were, for the most part, vocal and progressive advocates for their children. Parents in one of the groups made mention of having contact with what they termed "down and outers." By this, they meant other parents who had given up struggling with issues of having a child with disabilities. From my own professional experience, I have encountered parents who continue to work from a story of shame and sorrow. I think, in some cases, those parents do not want to hear that they should accept their child because their construction of reality is based on subjugating cultural discourses. There are other parents who are probably not at all interested in the political dimensions of service provision and still others for whom chronic sorrow is a very real and resonant experience. And, yes, I have also encountered parents "in denial." It is important to note that the adoption of constructivist principles, particularly the idea of deconstruction, can take different forms and deal with different kinds of issues than those presented by the stories of parents in the current study.

One of the main premises of narrative therapy is to help individuals re-author their lives, based on their own stories, rather than on the stories of others (White and Epston, 1990). These

results show how some parents have managed to do that often in the face of attempts by others to impose subjugating realities. Parents suggested that helping relationships work when professionals acknowledge that, in many respects, "the parent knows best." I think they have some good advice.

Unmasking the Dominant Story

One of the theoretical concepts underpinning the work of Narrative Therapists is the idea of the different story. According to White and Epston (1990), "those aspects of lived experience that fall outside of the dominant story provide a rich and fertile source of the generation or regeneration of alternative stories" (p.15). One of the features of telling different or alternative stories is that they help to unmask or deconstruct the subjugating nature of the dominant story. In this respect, the narratives of parents in this study have identified several features of the dominant story about disability, about being the parent of a child labelled with disabilities and, somewhat surprisingly, about being a parent in general.

The dominant story, based on the analysis of these narratives, encompasses the following constructions. In keeping with critical orientation of this study, there is some exaggeration in my reconstruction of the dominant narrative. In relation to disability: it creates a pathological distinction about certain kinds of physical and intellectual differences which are arranged hierarchically according to severity. These particular kinds of differences are seen to be tragic and inherently detrimental to one's quality of life. They represent an economic liability to society and should be eliminated or reduced. For parents who do give birth to children with disabilities, this can lead to the feeling that they have done something wrong. Blackford (1993) describes this discourse as "the patriotic ideal for women (that) has been translated into a moral responsibility to produce children who are healthy, bright, and motivated enough to compete with children from

Japan and Germany for a dominant share of the economic battle ground" (p. 290). In this sense, disability acts as a mechanism of social control for all parents.

In relation to being the parent of a child with disabilities: the dominant story for parents is sympathetic and emphasizes grief and stress. For some people, this story about parents appears not to have changed from Olshansky's (1962) original conception of chronic sorrow which is:

The permanent, day-to-day dependence of the child, the interminable frustrations resulting from the child's relative changelessness, the unaesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child; all these join together to produce the parents' chronic sorrow. That so many parents bear this sorrow stoically is rich testimony to parental courage and endurance. (p.192)

Alternative stories about being a parent of a child with disabilities contradict this view. However, in mainstream discourse, these stories tend to be dismissed as exceptional cases. For example, certain parents might be seen as having exceptional personal qualities while other parents might be described as being in denial about the ultimate potential of their child and avoiding their own feelings of grief. The dominant story leaves little room for different kinds of experiences including humour, the idea that there are benefits to having a child with disabilities, or the possibility that parents can love and accept their children.

In relation to being a parent, culturally available stories about being a parent revolve around ideas that parents are completely responsible for their children's behaviour, and that parents ought to understand and strive to meet a mechanistic set of developmental milestones. The dominant discourse also creates the idea of the "super-parent" - completely involved in, and cognizant of, their child's development. Such super-parents are able to manage work and family

obligations, set firm limits and provide maximum stimulation for their child to grow and develop. Underlying the idea of the super-parent is the idea that parents are socially valued to the extent that they have produced and socialized potential winners in the global economy - straight A students who know how to compete, who were toilet trained at eighteen months and who said their first word at seven months; in other words - "perfect children." Perfect really means those children with qualities that are socially admired and valued. Nelson (1993), who is the parent of a child with disabilities, describes her interpretation of individuals who appear to work from these kinds of assumptions:

Sadly, I have found that people exist who actually think in terms of perfection and are unable to appreciate the differences in others. Misinformed, ignorant and, I think, cruel, these are the adults who teach their children nothing about tolerance, kindness or admiration (p.87).

Of course, the ideology that perfection is both possible and desirable is not without precedence. In political science it is one of the key underpinnings of fascism. In this respect, the identification of the dominant narrative on parenting is indeed very provocative. There are no perfect children just as there are no perfect human beings. Everyone is flawed, some more than others but the claim to perfection remains an insidious feature of dominant social narratives.

Different Stories - Deconstructing the Dominant Stories

Disability

Parents' stories in this study demonstrate that problems associated with disability are not inherent features of impairment. Disability is the result of ideological and structural barriers imposed on people with impairments by the dominant interests of the majority. Ideologically, this critical perspective on disability revolves around the fact that disability is not "bad" but that it is

“different.” These parents’ experiences, alone, deconstruct the idea that disability is always tragic. What they were told at the beginning of their child’s life about what their child’s life would be like, was often in direct contradiction to their lived realities. In other respects, problems were created by a chronic lack of accommodation, an often overwhelming intrusion by various professionals and rehabilitative discourses into their lives and perhaps, most importantly, an impersonal and indifferent bureaucracy.

Parents articulated a belief in the possibility of reframing ideas about disability where individuals are “not put in boxes” but where “everybody has potential and should be encouraged to develop the potential, whatever that potential is.” Parents described their realities, in many instances, as a case of tearing down walls in order to get the supports necessary to achieve this goal. Their stories suggested that elements of a disempowering and static evaluation of disability continue to underlie some systems within the communities in which these studies were conducted. A father in one of the groups, repeatedly made reference to his guiding philosophy which was “don’t say no until you know it is no”. In this respect, parents’ definition of disability represents a shift from what is deficient to what is possible. While this kind of philosophy is clearly not alien to the field of services for people with disabilities, apparently the ideal is a long way from the reality. This suggests the need for a more thorough evaluation of how disabling stories persist within various systems. In other words, what exactly is stopping the ideal from being realized?

Finally, the idea that some of the assumptions in people’s interpretations of the promotion of pre-natal care might be seen as a subjugating discourse may seem quite controversial. The analysis of parents’ statements, in this regard, is not meant to imply that such practises be discontinued. Rather, it suggests that the concern for expectant mothers and healthy (not perfect) babies can be balanced with the full knowledge that certain conditions are inevitable regardless of

anything expectant parents do or not do prior to or during pregnancy. Even if there is a preventable cause, blame does not help anyone. Balanced concern should also address assumptions about those conditions which can be detected prenatally. Down syndrome, for instance, may be viewed as a pathology, but within the lived experience of parents of children with Down syndrome, it can also come to be seen as a particular kind of difference. Expectant parents should be allowed to make choices with the full knowledge of these alternative stories, and not just on the basis of the pathological view. The perspective of the information for parents of children with Down syndrome in the literature review is an example of this more balanced approach.

Being the Parent of a Child with Disabilities

When the very first statement in the first interview focussed on the positive aspects of having a child with disabilities, I can honestly say I was somewhat surprised. While this probably speaks to my own assumptions of what I expected, it was an immediate deconstruction of the idea that being the parent of a child with disabilities is always sad and stressful. I actually had to probe a few times before parents talked about "problems." It is important to note that the parents in the first group were parents of older children. Three of the five families had children over 20 years old and the youngest child was 12. These parents, nonetheless, focussed on the rewards and not on how stressful or sad their lives had been because they had children with disabilities.

Parents in all three groups related that there were many times when they experienced sadness and guilt as well as some difficult and stressful times. They also described these issues as elements of their lives that they were able to overcome or move beyond. They made no mention of Olshansky's "permanent day by day dependence, interminable frustrations" or "deep symbolism" tied to the "unaesthetic quality of mental defectiveness" (p. 192). The second and

third interviews, in contrast to these pathologizing assumptions, culminated in parents bringing out wallet pictures of their children so that the co-moderator and I could see the children we had been talking about in our conversations. That their children were a source of pride - real people with faces and distinct personalities - does more than deconstruct the assumptions implicit in Olshansky's description of chronic sorrow; it utterly destroys them. It is an indication of how the view of parenting a child with a disability has changed in the last 35 years.

To assert that parenting a child with disabilities is not a universally sad and stressful experience is not a new idea. Certainly, the idea of positive outcomes can be attributed to a number of factors, including the availability of support, the meanings attached to disability, personal characteristics like self efficacy and resiliency and formal supports by trained and caring professionals. The current study seeks to add to this list of variables the idea of "discourse" or, more precisely, how parents in questioning the influence of the dominant story have renegotiated particular kinds of alternative stories about being the parent of a child with disabilities.

Qualitatively, many of the parents' narratives represented this kind of deeper meaning making. In two cases, parents referred to the idea that parenting a child with disabilities was, in certain ways, preferable to parenting a normal child. Several parents highlighted that they had people and positive experiences come into their lives as a result of having a child with a disability.

Conversely, they articulated a discourse from others which denigrated or denied this alternate reality. Parents mentioned that other people perceived their lives as being more dysfunctional than the reality. In some cases, parents saw this as ironic. In other instances, the pathologizing view was seen to have limiting effects. The admonition to not let disability affect lifestyle, mentioned in the results, is one example. In postmodern society, this intersection of older tragic stories with new more positive stories is a new feature of the discourse on the parenting of children with

disabilities. It is difficult to say that few assumptions are legitimate and more accurate to assert that the experience is truly individual and unique.

Being a Parent

The deconstruction of social narratives on parenting was somewhat of a surprise finding. The remark "Those bloody books" was made in reference to the issue of toilet training but I think the idea can be extended further. These parents recognize that what is taken-for-granted, by most parents, is probably not going to happen for their children with disabilities. Since most of the parents in this study also had children who did not have disabilities, they were more critically aware of particular elements in the dominant discourse on parenting.

Having expectations for children may be an inevitable feature of being a parent. Those expectations need to be reasonable and balanced with a notion of the personal autonomy of the child. When those expectations are based on unquestioned assumptions about achievement and unrealistic cultural ideals, there is evidence that the result is damaging to both parents and children. The example of eating disorders is a case in point. The condition cannot be divorced from cultural conditions which foster unrealistic ideals of female physical beauty while at the same time constricting women's control over many aspects of their lives. Young women with eating disorders are often characterized as being over-achievers and have come from families with rigid expectations and rules about achievement and appropriate behaviour (Minuchin, Rosman & Baker 1978).

Parents in this study, related that they have learned to emphasize small achievements, have fun with their children and give themselves breaks despite what the "bloody books" say they should be doing. In short, they appear to have developed a view of parenting based on the philosophy that they are doing the best they can. This is not indicative of a laissez faire attitude

about parenting so much as it is a more reasonable and balanced approach.

While parenting from a balanced approach seems like common sense, certain cultural phenomenon suggest that some parents continue to be guided by a different kind of perspective. There are beauty pageants for toddlers and it is still possible to see parents fighting in the stands at their children's sporting events. Enrollments in elite schools have risen sharply in the last two decades. Parenting decisions, for some, seem to be based on the taken-for-granted notion that such cultural practises will improve a child's chances for success in an increasingly competitive world. Another example of this is the political pressure on the public school system to impose more standardized testing and show evidence of the achievement of higher test scores. While this might be seen as a caricature of relatively few parents, it is difficult to argue that this discourse does not somehow touch every parent, whether their children have disabilities or not. The political dimensions of telling different kinds of stories, such as those stories of the parents in this study, cannot be ignored.

Parents' stories in this study present an alternative to certain social constructions of parenting. This alternative also represents a challenge to dominant socio-political and economic versions of society. Viewed from a wider perspective, empowering all parents to appreciate small gains, to cherish the importance of having fun with their children and, most importantly, to value, celebrate and reframe individual differences is a way to counteract the negative implications of society. It is philosophically significant that parents in this study spoke of the need for community and for building partnerships rather than barriers. Many of the themes derived from these interviews related to parents' desire for a different kind of world - in particular for a society in which all people are enabled and in which 'disability' is no longer a valid or useful construction.

Talle (1995) describes the society of the Maasai in Kenya in which disability is not a valid

construction. In the Maasai language, while there are words for specific kinds of impairments, there is no word for the western concept of disability. He further contends that in Maasai culture, descriptions of impairment refer to practical concerns of not being able to perform a certain function. According to his analysis, impairment is seen to be a difference that can be a bad thing, but it is seen to be neither stigmatizing nor a reason to remove a person with an impairment from view. It is simply a result of the way the world was designed by God. Parents do not have disabled children in the Maasai culture; they just have different kinds of children. Talle concludes:

They (the Maasai) both name the difference and mark it, but I argue that this indicates acceptance and a lack of fear of the different or abnormal. To give birth to a disabled child is not culturally defined as a crisis, requiring specific actions and precautions. It is part of life's experience. (p.71)

In conclusion to the discussion, I offer the philosophical hypothesis that some parents in our own culture are attempting to reconstruct a similar view about being the parent of a child who is different. As one parent put it, "You never think of your life as dysfunctional. Everybody else around you does. It's just different". In other words, it is a different story.

Contributions of This Study

This study has the potential to contribute to knowledge in the area of counselling and support of the parents of children with disabilities by elaborating a potential framework for counselling interventions based on emergent critical definitions of disability (Lenny, 1993; Oliver, 1993). According to Hornby and Seligman (1991), while there is an abundance of research into characteristics of families where children have disabilities, there is a dearth of literature on specific counselling strategies for working with this population. While this study has not defined a specific counselling strategy, it has suggested that many of the constructivist theoretical principles of

narrative therapy are evidenced in parents' stories about how they have adapted to having a child with disabilities.

This study has also described particular stereotypes or essentializations about parents of children with disabilities. It has suggested that, for these parents, change processes and the particular ways in which parents make sense of disability are varied and individual. In this sense, the study affirms the notion that counselling and parent support interventions need to be individualized and based on principles of empowerment (Dunst, Trivette & Deal, 1994) rather than generalized assumptions (i.e., Ziolk, 1991) about the experience of raising a child labelled with disabilities. In other respects, this study has questioned the need, in all cases, to approach the task of counselling parents of children with disabilities with "awe and caution" (Ziolk, p. 31). Quite the contrary, I think some of these parents' stories suggest counselling can be approached with openness and respect and can also include a sense of humour. Philosophically, this study has sought to deconstruct the mystique surrounding certain "tragic" assumptions about the parents of children with disabilities.

Finally, this research has contributed to the field of counselling by adding to the research paradigm of more critically informed counselling theorists. Postmodern approaches to counselling present serious theoretical challenges to more traditional counselling theories. A large part of this challenge relates to meta-theoretical concerns about the limits of positivist inquiry in counselling. This study has pointed out particular examples how interpretations of traditional perspectives on psychology can tend to become over-generalized and thus subjugating for parents and children. From a positivist point of view, statistical knowledge about populations cannot be inferred to an individual. This study has elaborated examples of what happens when people over generalize empirical knowledge. Particular elements and rich detail are missed and the full context is not

understood. As an aside to this and to emphasize the point, I have met the child who “displayed cruelty to animals”; she is not a psychopath.

Limitations of the Study

This compilation of parents’ stories is not intended to be representative of the larger population of parents with disabilities. In most qualitative studies, this lack of generalizability is a tradeoff for data which provides a greater depth of perspective. In reviewing other qualitative studies about positive adaptation (Bennett, DeLuca & Allen, 1996; Knoll, 1992; Trute & Hauch, 1988), however, many of the descriptions in the current study suggest findings which are qualitatively very similar. In any case, the purposes of this study are exploratory and theoretical. This research was designed to provide an interpretive rather than inferential body of data.

Another limitation of the study was that it did not include individuals who would have difficulty sharing their experiences in this kind of setting. This study is also limited by the fact that it represents the stories of parents willing to participate in a group setting. It also includes only those stories parents felt comfortable in telling. Thus, there is the possibility that only the stories of articulate and outspoken individuals were heard. Certainly, it was the case that many of the parents were strong advocates and that they did tend to have more to say about critical aspects of disability. To be sure, there were parents in each of the groups who talked more than others. What parents would have said in individual interviews might have been qualitatively very different.

The geographic limitations in this study included that it was conducted in just two communities in the interior of British Columbia. To that end, the concerns of parents may only reflect the concerns of parents living in northern communities. As most research is conducted in large urban areas, the rural perspective is often ignored. In this respect, the demography of the

study is a strength as well as a limitation, in that it provides information useful in northern centres.

This study cannot make any inferences to the population of parents of children with disabilities in general nor even to all parents living within the geographic area in which the study takes place. The stories of the parents in this study varied, but they were generally told from a progressive and involved viewpoint. Parents were mostly from two-parent households, had actively sought out and utilized a variety of services and supports and were well educated and middle class. In this respect, this study does not provide information that elaborates cross-cultural perspectives or that includes the stories of parents from a varied socio-economic backgrounds.

Another limitation of the current study involves the lack of contrasting perspectives. Parents spoke a great deal about other people, particularly professionals. In presenting parents' stories, inferences about other people's assumptions are based on parents' interpretations and are not balanced by the perspective of those individuals the parents mentioned. Although parents tended to be especially negative about the medical and social welfare systems, their stories cannot be viewed as evidence that these service systems are in need of radical reform. These systems and their relationships to parents are highly complex. On the other hand, they do point out some problems which might be the subject of future, more thorough research.

Recommendations

In this section I make recommendations based on the analysis of these interviews. I address the areas of counselling, professional education, and future research.

Counselling Parents of Children with Disabilities

One of the purposes of this study was to inform counsellors about how to deal with counselling situations involving parents of children with disabilities. The following recommendations are based on the narratives of parents in this study.

If a counsellor has no experience with a family member with a disability, it is important for him/her to acknowledge that he/she lacks experiential knowledge. Personal assumptions about what it might be like are not the equivalent to having individual experience. Hanline's (1991) position that parental adaptation and coping is unique and individual is appropriate in this regard. It is best to simply state that you do not know. In this respect, other parents of children with disabilities are often an effective source of emotional and psychological support.

With some parents, counsellors ought to be prepared for contradictions. The development of new ideas about difference takes time. Parents' stories in this study confirmed that their individual experiences with positive adaptation varied considerably from time to time, particularly when they encountered a barrier such as a lack of disabled parking spots or another individual's essentialized description of themselves or their child. I think it is very important for counsellors to take a wider view of the difficulties parents of children with disabilities face and to be aware that those difficulties are often systemic rather than a case of individual inability to cope. Viewing disability as a feature of the disabling society means confronting both structural and ideological barriers. Clearly, this represents an enormous stress on parents as those barriers continue to be pervasive features of mainstream society.

When dealing with issues of a child's behaviour, there is a context in which that behaviour occurs and, without being in that context, a counsellor cannot be certain whether a strategy will work or not. Therefore it is important to acknowledge the limits of expertise and avoid rigid prescriptions. Parents in this study also related that it is important to approach behavioural situations with a caring and open-minded attitude. Related to this, written information or assessment related to a child's behaviour problems should be conveyed in such a way that parents understand it in light of their own experience. Behaviour management plans are not prescriptions

with definitive outcomes; they are individual experiments that may or may not achieve a desired result. If behavioural reports are written, professionals should review and discuss the content of those plans with the parents present.

Counsellors need to share information with parents and avoid the tendency to underestimate parents' ability to make sense of information about disability. Having information about their child's impairment, available services and government policy initiatives was important for these parents. Sharing of information with parents acknowledges and validates their expertise and begins to build a partnership. Many of these parents' stories also suggest that historical and sociological information about disability issues was a key component in how they made sense of a child's disability.

"Don't say 'no' until you know it is 'no'." This may involve putting aside pre-conceived notions about what is possible for individuals with particular types of disabilities. Although some things may not be possible, parents can discover these for themselves. Parents were clear in their assessments of how some professionals appear to impose limits through a static assessment of disability. Not saying no until you know it is no also needs to include the interests of the child. While this study did not explore in detail the intersection between parent and child interests, there are probably some cases where parents' desires are contrary to the child's interests.

It is important for counsellors to recognize the value of parent support groups and that, for some parents, the counselling they get in such groups will be superior to what an individual counsellor can provide. Many of the parents also stated that their groups acted as a mechanism for sharing and accessing practical information in regard to meeting their child's needs. Interminable frustrations with bureaucracy appears to underlie and augment the value of support groups in this regard. Parents' stories suggest there may be vested political interests in maintaining the status

quo of social service bureaucracies. Collective action on the part of parent advocacy groups represents an important change to this status quo.

Counsellors and support people should listen to parents. While this is important in any helping relationship, in issues involving disability there is a tendency to miss important details in parent's narratives. Sometimes clinical agendas have a way of interfering with what parents perceive as more important day to day issues. These balances may be difficult to achieve. In this respect, I do not think counsellors have to denigrate the work of rehabilitation professionals but can validate parents questions and concerns with regard to achieving an appropriate balance.

Counsellors can help parents deconstruct assumptions from the dominant discourse that are sources of frustration and stress. They can look for those problems which can be externalized and situated within dominant narratives about disability and being normal. It is also important to validate parents' alternative stories about themselves and their children. In particular, counsellors need to pay attention to the value of "de-medicalizing" and "de-awfulizing" the experience of raising a child with disability. The fact that nearly all the parents in this study mentioned some component of dealing with other people's "horrible pictures" suggests that parents continue to have to deal with this taken-for-granted view of disability.

Professional Education

The education and training of professionals who work with individuals labelled with disabilities has been dominated by the concept of normalization. The deconstruction of disability suggests that there is a need to re-evaluate some of the basic premises of this model of service delivery. The education of professionals needs to include views about normality from the perspective of individuals with disabilities as well as their families. Such education also needs to lead professionals in training to question the idea that individuals with disabilities are valued if

they are more like the majority.

The education of professionals and para-professionals needs to focus on a deeper discussion of the social construction of normality as well as disability. Professionals need to be aware that this debate goes further than simply a debate about the correct language to use in referring to people with disabilities. To be sure, some of the language coming out of the disability rights movement provokes societal concerns for correct language. Some people with disabilities have begun to refer to themselves as “crips” while others have sought to rid the language of the patronizing term of “challenged” (Shapiro, 1993).

With regard to terminologies, educational programs need to emphasize the difference between language which identifies a condition of impairment and language that essentializes or labels. The distinction between impairment and disability is important. The well articulated position that the condition of functional difference becomes disabling when that difference is viewed as tragic applies to many individuals with impairments. In contrast, having an impairment from a non-disabled perspective, becomes a case of hopelessness. This tends to construct people's realities in one direction and ignores the possibility of different outcomes. It should be cautioned that the tragic narrative on disability is a very old story and deeply ingrained in cultural and language practises, so that a full discussion of this issue requires time and careful reflection. Education, in this respect, is not just about the “correct” choice of words; it involves looking at how meaning has been negotiated historically and politically. In some cases, this brings to light perhaps difficult and provocative issues like the example of fascism mentioned earlier. Professional education about disability need not avoid larger political questions.

While the education of professionals working in the medical system may be more complex and technical, there is a need to humanize and balance medical professionals' views about physical

and mental impairments. Inviting parents who have had positive experiences in raising children with disabilities to be guest lecturers would be an excellent starting point.

Education needs to encompass a balanced view of disability and should include both the views of individuals with disabilities and those of their parents. Critical and deconstructed definitions of disability should be included in curricula for professionals and para-professionals working with this population. The education of professionals should also include the education of all professionals, and not just those working specifically in disability-related fields. An ideal situation would be for all curricula in the helping professions (health care, social work, education and psychology) to include a course in disability studies.

Future Research

This research project brought together three topics: evolving critical definitions of disability, narrative constructivist theories of counselling, and the counselling and support of parents of children with disabilities. Research was exploratory and theoretical. It provided a beginning qualitative evaluation of several key principles within each area of interest.

This study suggests possibilities for both practical and theoretical research. Practically, the results of this study suggest narrative therapy strategies that could be used for counselling parents of children labelled with disabilities. It has delineated, among others, the "problems" of comparing and horrible pictures. From a narrative therapy perspective, these are externalizable problems which can be deconstructed. Single case studies of actual counselling interventions utilizing externalizing and deconstructive questioning protocols would further elaborate this process, possibly with different kinds of problems.

Comparisons of narrative approaches to alternate approaches to counselling would be useful for elaborating the relative strengths of narrative therapy with particular populations and in

specific situations. Similarly, research could be designed that examines outcomes for parents who receive counselling from counsellors trained according to a more critical view of disability. There is also a need to examine whether differences in counselling approaches exist between counsellors who have direct experiences with people with disabilities versus counsellors who have none.

Theoretically, similar studies such as the present one, need to be applied to professionals' perceptions of families, the perceptions of children with disabilities and the perceptions of their siblings. The topic of sibling relationships was raised in all three interviews and provides a good starting point for a similar analysis. It would also be interesting to contrast similar data with the views of parents of typical children on what they think it would be like to have a child labelled with disabilities.

Above all, this study speaks to the general need to include the voices of those being studied in the research process. This inclusion provides a check on the tendency to essentialize the experiences of those who have been all too often objectified within other research paradigms.

Conclusion

This study began two years ago and was motivated by a particular story about a student with disabilities and her parents. Because of issues of confidentiality, I cannot relate the details of that story. Suffice to say, it is not an example of positive outcomes like many of the stories in the current study. A detail that I will relate is that this student asked me "why can't my parents understand that this is just the way God made me." Two years later, I am still not sure that I can answer her question, although I do think that this study has provided some insight into the depth of the problem.

The parents in this study were parents who found ways of making sense of disability which I would describe as pioneering. It was not that long ago, after all, that institutions, segregated

classrooms and restrictive service options were the norm in this province. I started working in the field of services for people with disabilities in 1984 during the final years of exclusionary service practises. I can recall people's opposition to the changes towards inclusive schools and the move of residents out of institutions into group homes in the community.

The parents in this study represent a new generation of parents whose children have gone to school in their own neighbourhoods, have participated in aspects of the communities in which they live and have lived at home with parents who love and accept them for who they are. These children's different stories have yet to be told. It is my hope that in years to come when their stories are widely available, they may be able to provide a more compelling answer to my student's question. More importantly, I would hope that the question is less often asked.

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Appendix A Demographic Questionnaire for Focus Group Participants

Please take a minute to complete the following questionnaire. The following information is requested in order to include in the study some descriptive information about participants. Please note that this does not require you to provide your name. It will be included in the completed study as summary of characteristics of all participants.

1. In what age category do you belong?

- Under 25
 25 - 34
 35 - 44
 45 - 60
 60 or over

2. Are you

- Male ?
 Female ?

3. Are you

- the biological parent of your child ?
 the adoptive parent of your child ?
 foster parent
 Other caregiver _____

4. In what combined annual family income category do you belong?

- under \$20,000
 \$21,000 - 35,000
 \$36,000 - 49,000
 \$50,000 - 65,000
 \$66,000 - 80,000
 \$81,000 and over

5. How many children do you have including your child with disabilities? _____

6. What is the nature of your child's impairment or disability?

- Developmental delay or mental handicap
 Learning disability
 Physical disability or mobility impairment
 Hearing impairment
 Visual Impairment
 other _____

7. Is your child's impairment

- Congenital - apparent at birth
 Acquired - the result of an accident or illness after birth

8. In the past have what kind of psychological emotional supports (counselling) have you sought for yourself?

- Services of a professional counsellor, psychotherapist or therapist
 Supports offered by other professionals working

with your child (ie - child development centre staff, school teachers etc.)

- Supports from family members
 Supports from friends
 Supports from other parents of children labelled with disabilities
 Have not sought psychological or emotional supports
 Other _____

9. What is your marital status?

- married
 divorced/ separated
 widowed
 single

10. What do you consider best describes your ethnic origin?

- European
 Indo-Canadian
 First Nations
 Chinese
 Other _____
 (specify)

11. What is the highest level of education you have achieved

- Elementary school
 Some secondary school
 Secondary school graduation
 Some college or technical training
 Some university
 Bachelor's degree
 Some Post graduate school
 Post graduate degree

Appendix B Summary Tables of Demographic Data

Group	number of parents	number of families	number of children
Mill Town	5	4	4
Lakeville 1	7	5	5
Lakeville 2 (CDC)	3	3	6
total	15 parents	12 families	15 children

Table 5 - Summary of the three groups

Parent type	n=	Age of children	n=	Type of disability	n=
foster parents	1	preschool 0-5	5	developmental	8
adoptive parents	2	elementary 6-12	5	physical	4
biological parents	12	secondary 13-18	2	learning	3
		adults 19+	3	(multiple)	(4)
totals	15		15		15

Table 6 - Type of parent, age of children, type of disability

parent gender	n=	marital status of parents	n=	family income	n=
fathers	3	married	13	under 20, 000	2
mothers	12	single	1	21-35,000	2
		widowed	1	36- 49,000	1
				50-65,000	6
				66-80,000	1
	15		15		12

Table 7 - Parents' gender, martial status, family income

parents' education	n=	age of parents	n=	Child Gender	n
Secondary grad	2	25-34	2	female	10
Some college	8	35-44	7	male	5
Some university	4	45-60	4		
Bachelors degree	1	60 +	2		
totals	15		15		15

Table 8 Parents' education, age and child's gender

number of other siblings	n=	prior experience with counselling	n=	ethnicity	n=
0	1	trained counsellor	4	European/Canadian	13
1	6	other professionals	11	Asian	2
2	4	family & friends	11		
3 or more	1	other parents	10		
		none	2		
total	15		n/a		15

Table 9 - Number of siblings, parents' prior experience with counselling and ethnicity

Appendix C Focus Group Interview Guide

Set-up - ensure all equipment and room is set up and ready for participants. Participant will each have name tags (first names only). Coffee and snacks will be provided

Warm-up

Introductions - before we begin I wonder if I could take a minute to get to know everyone here. Could you all tell me something about yourselves and try to think of something that will help me remember your name?

Overview and establishment of some discussion guidelines

The reason I am here today is to ask you some questions about your experiences in raising a child who has been given a label of disability and to discuss some of the ways you and your families have learned to adapt to the situation. Before I start the interview, I should probably point out a few things about the study. This is a study of interest to counsellors and other professionals who are in a position to help and support parents of children with disabilities. While I am a student in counselling, my primary purpose today is not to provide counselling to you but to gather information for a study. If people find that certain issues are difficult to talk about and that you require some emotional support I would ask that we find a way as group to deal with that after the session is over. I appreciate that to share your personal stories may cause some discomfort and I truly appreciate your willingness to share as openly as you feel comfortable with. I'd like to stress that I will not push you to share issues beyond your own level of comfort.

Explain presence of co-moderator(note taker, observer); review that session will be taped and ask if people have questions particularly with regard to any issues mentioned in the letter of informed consent - risks, benefits, confidentiality, issues related to audio taping. Encourage if necessary concerns with regard to identifying characteristics of child or previous relationship with moderator in another professional role.

Focus 1 (general description of issues in raising a child with disabilities)

QUESTION: I would like to begin by asking everyone to share their experiences in raising a child with disabilities.

What has been your experience in raising a child labelled with disabilities?

<moderator listens , reflects and clarifies points>

<co-moderator during this time notes general themes>

Focus 2 (externalization of the problems)

POSSIBLE DIALOGUE : Thank you for sharing those stories. I'd like to take a moment to just summarize some of the things you've talked about particularly the kinds of challenges or problems you have faced and are currently facing. What I would like to do is to give the problems a name and to pick what the group sees as the three most relevant or important issues. My co-moderator is going to help out by writing them down.

< moderator leads discussion> <co-moderator records on flip chart>

Focus 3 (deconstructive questioning)

Ask specific questions about the problems parents identify when appropriate .

<the moderator uses deconstructive questions to elicit parents' stories about how they have related to or changed the problem in their lives

< the co-moderator assists by re-directing moderator back to deconstructive questions>

Deconstructive questions : (these are a general guideline and can vary depending on the problem being discussed)

How has [*the problem*] affected you in the past and how has your relationship to [*the problem*] changed?

How do you think other people's ideas about how [*the problem*] is supposed to effect parents of children with disabilities strengthens its position?

When [*the problem*] came into your life how did it take over?

How did you finally defeat [*the problem*]?

Appendix D Copy of Informed Consent

Date, 1997

To Whom it May Concern:

As a graduate student at the University of Northern British Columbia, I am conducting research on the implications of critical and constructivist theory for the practise of counselling and support of parents of children with disabilities. Findings from this research will assist counsellors and other helping professionals in their understanding of the unique sensitivities required in working with families where a child has disabilities.

I would like you to participate in my research study titled "Telling a Different Story: Implications of Constructivist Theory for the Counselling of Parents of Children Labelled with Disabilities". The goal of this research is to elicit the parents' stories of their experiences in raising a child with a disability with particular attention to issues which arise from emerging theoretical perspectives within the fields of counselling and disability studies. Briefly these issues touch on but are not limited to, assumptions and stereotypes about your experience as parents, the influence of professional service systems, the social "meaning" of disability and your own perceptions about the need for counselling and support.

If you agree to participate in the study you will participate in a focus group session with 4-5 other parents of children with disabilities whom are already members of your current group. Each session will last approximately 90 minutes. You will be asked to describe your family's experience and to participate in a small group dialogue on issues such as those mentioned above. a focus group method of research is a semi-structured group interview with the added dimension of a group discussion.

There are potential benefits in your participation. Group dialogue can have therapeutic benefit for individuals whose experience is similar. Your participation may reaffirm your commitment to your children and assist you in clarifying your strengths as a parent of a child with a disability. You also have a chance to contribute to improvement in professional practise as it is a goal of this study to define "best practises" as defined by those individuals who are in a position to receive services. This study works from the perspective that parents are experts in their own needs for counselling and support. a copy of the final study will be made available to each focus group cohort for your perusal.

There are also potential risks to participation in a study of this nature. These include the chance that the experience may be emotionally draining or upsetting, that you may not feel entirely comfortable in sharing issues in this setting and that you may not have shared certain of your experiences with others in your group which may subsequently alter your relationships with them. The interview also requires your time. In order to minimize these risks the following safeguards are in place: You are free to withdraw from the study at any time. You will not be pushed to share anything that causes you to feel uncomfortable. If issues do emerge which prove troublesome post session de-briefing will be provided and if necessary assistance with a referral to counselling. The interview session will be time limited. I will endeavour to keep within the 90 minute time allotment and will not continue past two hours.

You should be aware that the focus group sessions, while they may have a therapeutic benefit, are not intended to be group counselling sessions. If, as a result of this study, you and other participants identify a need for a continuing or additional support I will ensure that this information is shared with appropriate agencies in the community. It is important to understand that my primary role is as a researcher and not a counsellor

Participation in the study is completely voluntary and you will be free to refuse or stop at any time without penalty. All focus group sessions will be audio-recorded for the purposes of transcription. Your identity, your child's as well as any identifying characteristics of your child will be kept strictly confidential. a pseudonym will be used for you and your child for the purposes of transcription. The actual tapes will only be heard by myself, my co-moderator, my advisor and a transcriber who will have access to the tapes only as long as it takes to transcribe them. Once transcribed the tapes will be erased.

If you have any concerns or require further information, please feel free to contact the following:

Jay Goddard
Lakeville, B.C.
Phone : 989-1170

Ron Lehr. PhD
Faculty of Health and Human Sciences
University of Northern British Columbia
Phone : 960-5572

Please read the following paragraph, and, if you agree to participate, please sign below.

I agree to participate in the research study as described above. I understand that any information about me or my child obtained from this research will be kept strictly confidential. I further understand that I can withdraw from this research at any time without penalty.

Signature _____ Date _____
Investigator _____ Date _____

Please place your initials here acknowledging receipt of a copy of this consent form. _____

Appendix E - Dependability Check

Dependability Check

The criteria for determining whether a statement reflects deconstruction is as follows:

- 1) The statement questioned or dismissed what is offered as legitimate knowledge and was perceived by the narrator as a cultural value or assumption,
- 2) The statement appealed to individual validity of interpretation rather than "widely held beliefs",
- 3) The statement pointed directly to a contradiction with taken-for-granted assumptions about the nature of the phenomena in question
- 4) The statements contextualizes or reframes the issue .
- 5) The statement or passage identifies a subjugating cultural discourse

Examples: Examples of deconstructive statements:

tragedy is in the eye of the beholder,
it's okay to be disabled,
you are allowed to feel whatever you feel.

Examples of Non-deconstructive statements or ideas include:

What parent does not wish that their child could be normal?,
the tragedy of having a defective child,
a pattern of feelings and responding.

Cultural assumptions and values about disability and being the parents of a disabled child:

Disability represents a condition of pathology - It is a disease, defect or abnormality.
Parents of children with disabilities experience inordinate amounts of grief and stress.

Instructions - Read the statement. Circle the number(s) of criteria you think apply. Underline key sentence or phrases and add brief comments which you. If you think none of the criteria apply to the statement do not circle anything and write non-deconstructive.

The first statement is completed as an example