PARENTS APPRECIATING THEIR ADULT CHILDREN WITH DOWN SYNDROME

by

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ABSTRACT

This study is done from a social constructionist perspective where the prevailing views on Down syndrome, and parenting children with Down syndrome are regarded as dominant cultural portrayals or constructions. After reviewing the development of the biomedical, historical, and cultural forms of discourse about Down syndrome, and parenting children with Down syndrome - constructions I think are negatively skewed - I focus on the rarely considered appreciative experiences involved in parenting a child with Down syndrome from birth to adulthood.

With the steady increase and sophistication in genetic testing, prospective parents of children with Down syndrome now face critical decisions regarding the life of their fetus and their future as parents. In the absence of other, more appreciative views, prospective parents and health care professionals draw on dominantly negative views to make momentous decisions.

For this study, nine parents were interviewed who had experienced life with a child with Down syndrome from birth through to adulthood. Analysis of the data produced three themes. The first theme does not address specific appreciative experiences but instead looks at a consistent process of reconstructing meanings that appeared to occur in order for each parent to first accept their child with Down syndrome. Each parent appeared to go through an acceptance process each in his/her way and in some respect said "yes" to this child who was different from what they had expected. The second theme looks at experiences parents appreciated regarding their child with Down syndrome as a teacher. Parents repeatedly shared how these children taught them so much about themselves, life and the world. The final theme looks at caregiving and what experiences parents appreciated about that role involved in raising their child with Down syndrome.

This thesis examines Down syndrome through an appreciative lens and challenges some of the traditional imaginings about what it might be like to parent a child with Down syndrome. This study is about sharing new meanings and images about Down syndrome and of parenting a child with Down syndrome from birth to adulthood and the importance of balanced information being shared in the encounters between providers of genetic information and prospective parents.

Dedication

This research is dedicated to my brother, Michael Shawn Hill. I appreciate having had the chance to experience life with a brother with Down syndrome. He lived for forty-six years and had a profound and powerful impact on my life.

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Chapter 1

Introduction

Down syndrome is one of the most frequently occurring chromosomal anomalies found in humans and has become one of the most controversial, researched and discussed genetic variations of human kind. However, dominant Western historical and cultural depictions or constructions of Down syndrome have portrayed it as a serious disability, an abnormality, and a disease, something that should be either prevented or cured. Within these dominant constructions, the birth of a child with Down syndrome has commonly been viewed as a tragedy and greeted with feelings of loss and disappointment. These constructions of Down syndrome support the genetic testing programs for Down syndrome that currently continue to expand and develop (Blumberg, 1994; Elkins & Brown, 1995; Glover & Glover, 1996; Williams, 1995). As prenatal diagnosis becomes more common, an increasing number of prospective parents are faced with difficult decisions. Presently, many fetuses that test positive for Down syndrome are aborted. This situation seems reasonable considering the dominant view of Down syndrome is one of ongoing burden.

At the same time as genetic testing is becoming more prevalent, increasing numbers of people are starting to question and challenge the current dominant constructions of Down syndrome. More people are talking about ways in which people with Down syndrome are of value to society and how they enrich people's lives. With this study I want to continue to open spaces for more appreciative voices to be heard in the cultural dialogues on Down syndrome and parenting a child with Down syndrome. I want to enrich the literature that is now available and suggest new possibilities for parenting a child with Down syndrome. Adding appreciative perspectives will further expand the information base available for health professionals. These professionals share critical conversations with prospective parents prior to the difficult, complex decisions parents must make in our genetically advanced world. During this pre-birth reflection time on whether to abort or keep a fetus with Down syndrome, it is important that parents have balanced information with which to make informed decisions.

The Research Problem

The purpose of this inquiry is to explore experiences primary parent caregivers appreciate about living with a child with Down syndrome from birth to adulthood and to add to the traditional understandings of parenting a child with Down syndrome.

Research Question

What experiences are appreciated by primary parent caregivers living with a child with Down syndrome from birth to adulthood?

Impetus for Study

The impetus for this study originates from my stance as a person and my belief that as people we socially construct our meanings together. I think that it is possible to construct new and different meanings in dialogue with others. As well, my personal experiences within my family and in my career have contributed to my passion for this topic.

Personal Stance

I come from a social constructionist perspective. Social constructionist inquiry is most interesting for me because it focuses on a social approach, valuing relationship over individualism and how we turn to each other most often in language to construct and share our meanings. Gergen (1994), a forerunner in social constructionist thought, discusses the eschewing individualist tradition and the growing support towards giving value to relationship over isolation. He states that people in relationships move toward collective agreements on what is real, rational, and right, and articulate these agreements in their forms of language. Gergen (1994) states that regardless of our society or culture, we develop working languages for carrying out our collective lives. The working language and collective agreements in Western society regarding parenting children with Down syndrome have traditionally focused on pathology.

Consistent with the social constructionist perspective, Cooperrider and Srivastva (1987) have developed a theory of organizing and a method for changing social systems labeled "appreciative inquiry". I intend to use a basic process of appreciative inquiry in this thesis - to begin with a grounded observation of the "best of what is"(Cooperrider, 1998, p.12) to expand on the current working language and collective agreements about parenting a child with Down syndrome. This decision to take an appreciative stance, to focus on the "best of what is" comes from my life-long experiences of living with a brother with Down syndrome.

Personal Experiences - Family

The driving force behind this thesis is my experience with my oldest brother, who was born with Down syndrome in July of 1950. My life has been full of a wide variety of experiences connected specifically with living and working with my brother. My parents, who were at the forefront of my brother's caregiving, faced challenging, frustrating, and frightening experiences, as well as joy filled and rewarding experiences. They openly shared their love and appreciation about experiencing life with a son with Down syndrome and were the individuals that most directly contributed to my current constructions of Down syndrome. Furthermore, as a sibling, I had many of my own experiences that I appreciated. Living with this appreciative dialogue within my family and with the knowledge that there was a lack of appreciative voices in formal research, I chose to follow this passion and engage other parents' voices in dialogues regarding appreciation.

Personal Experiences - Career

Another driving force behind my wanting to do this study originates from my work as a teacher and counselor and working with people who have been labeled "mentally challenged" or "developmentally disabled". These labels are often focused on how much extra funding is provided for a child within the school system and so serve legitimate purposes. However, these labels focus specifically on maladaption and inadequacies. Segal (1986) uses the words of Norman Garnezy, a University of Minnesota psychologist, to emphasize the common negativity of the counselling professions, "We have directed our energies to study maladaption and incompetence.

Our mental health practitioners and researchers are predisposed by interest, investment and training in seeing deviance, psychopathology, and weakness wherever they look" (p.9). This study may facilitate discussions on new or different approaches to labels applied to people with Down syndrome.

Significance of the Study

Persons with Down syndrome have suffered a long history of persecution. The history of people with "mental handicaps" from Ancient Greece, through the Middle Ages, to present day practices is full of vivid accounts of oppression. The meanings that have been constructed over the last century about Down syndrome, and the widespread use of genetic testing, has moved us as a society to where there appears to be a determination to prevent this "condition". The importance of this study rests in my fear that the increase in genetic testing represents an increase in negative perceptions of persons with Down syndrome within our society. These negative perceptions support the abortion of fetuses with Down syndrome. With the increased availability and subsequent use of genetic testing, fetuses with Down syndrome have become particularly vulnerable. Growing numbers of prospective parents are faced with making life or death decisions regarding a fetus with Down syndrome. This study is not about judging prospective parents' final decisions as right or wrong as each genetic decision is unique and influenced by multiple factors. However, for this critical decision making process, parents deserve a broad picture of what it is like to share one's life with a child with Down syndrome from birth to adulthood so that prospective parents' decisions are well informed.

From a constructionist perspective, the meanings constructed about Down syndrome are continually negotiable. It is important to question taken-for-granted assumptions about Down syndrome and what it might be like to experience parenting a child with Down syndrome and offer other meanings. Health professionals (doctors, specialists, genetic counselors, and/or counselors) play an important role in supporting prospective parents in this deliberative process by providing a wide range of considerations, perspectives and options. The meanings and images created about parenting a child with Down syndrome from the appreciative dialogues contained in this research are intended to add breadth to factors considered by prospective parents and the health care professionals that assist them, in making decisions about the future of fetuses with Down syndrome.

Organization of Chapters

This study is presented in five chapters: In Chapter 1, I introduce the topic, which includes the research problem and question, the impetus for and significance of the study. In Chapter 2, I present the literature review. In Chapter 3, I outline my research methodology, description of my approach, and ethical issues and considerations. In Chapter 4, I present analysis of my findings and in Chapter 5, I share a summary of the study, my conclusions, limitations of the study, and implications for further research, practice and education.

Chapter 2

Literature Review

Social Constructionist Inquiry

The traditional understandings about Down syndrome and parenting a child with Down syndrome have been constructed by Western society within conversations that give us our sense of reality. Over the past 100 years, since the label "Down syndrome" came into existence, the working language used to describe Down syndrome provides an enlightening perspective on how Down syndrome has come to be generally understood. In these taken-for-granted constructions, Down syndrome is conceived as something to be cured or prevented. The terms in language used to describe the condition referred to as Down syndrome speak for themselves: mongoloid idiocy, an imperfection in DNA, fetal abnormality, choromosomic abnormality, severe, disabling, genetic disease. People with Down syndrome have been labeled with titles such as mongoloid idiots, mentally retarded, mentally handicapped, disabled, slow, and mentally challenged. Giving birth to a child with Down syndrome has been described as a "tragic instance" (Berube, 1996, p. 25). While not discounting that there are biological differences in a child with Down syndrome, these differences have been inordinately skewed to mean pathology and negative experience. In this study, I am adopting a social constructionist perspective and want to offer other experiences to these dominant, cultural dialogues on Down syndrome and parenting a child with Down syndrome. I would like to elaborate now on what I mean by a social constructionist perspective.

Throughout history, human beings have challenged themselves to discover the meaning of knowledge, reality, and truth. During the Renaissance, the scientific method developed as the perceived method of uncovering what was real and what was true. Scientists were considered capable of supplying objective glimpses of truth and reality. However, over time have come postmodern movements that challenge the belief that there is one "truth" or one accurate, objective way to understand or to know the world. The belief in the capacity of language to represent the world in an accurate and objective manner is being challenged. Broader ways of viewing or knowing, reality and truth continue to develop and today there are a wide range of active inquiries devoted to understanding the construction of self and world. One of these ways is called the social constructionist movement. Ernest (1995) states that there are as many varieties of constructionist positions as there are researchers. Gergen (1999a) shares that there is a pervasive tendency to view current constructionist inquiry as a unified front. However, he states that there is a wide range of variegated and overlapping ideas and practices with three major movements in constructionist inquiry – ideological, literary-rhetorical and social. Each of these three major sources of contemporary construction shares in their critique of traditional views of language and authority but differs in their mode of critique and their political investments. For the purpose of this paper, I will be coming from a social constructionist position.

According to Gergen (1994), renowned scholar of social construction, there are several important assumptions that are made by a social constructionist science:

- The terms by which we account for the world and ourselves are not dictated by the stipulated objects of such accounts.
- The terms and forms by which we achieve understanding of the world and ourselves are social artifacts, products of historically and culturally situated interchanges among people. [We understand the world and ourselves within the context of relationship.]
- The degree to which a given account of world or self is sustained across time is not dependent on the objective validity of the account but on the vicissitudes of social process. [Meanings are continually negotiable until we find something that works for us. People use satisfying meanings for themselves in discussion with others or renegotiate their meanings should new experience find them inadequate.]
- Language derives its significance in human affairs from the way in which it functions within patterns of relationship.
- To appraise existing forms of discourse is to evaluate patterns of cultural life; such evaluations give voice to other cultural enclaves. [In language there are taken-for-granted patterns, repetitiveness, and engrained patterns. Thus language used in local ways excludes other experiences.] (pp.49-54)

Gergen (1999b) states that "the vast share of human action grows out of interchange and is directed into further interchange….Words are not 'my own' the authorship is misleading. Rather, I am a carrier of relationships, forging them into new relationships" (p.6).

Murphy (1997) points out the constructionist view argues that knowledge and reality do not have an objective or absolute value or that there is no way of knowing this reality and that people interpret and construct reality based on their experiences and interactions with their environment. Once truly entering a constructionist framework it is "very difficult to accept any particular reality posits, truth claims, or moral principles as transparent, foundational, or beyond construction…constructionist thinking tends to remove the grounds for any strong claims to the real and the good"(Gergen, 1999a, p.6).

By using a social constructionist framework, I invite reflection on our society's taken-for-granted assumptions regarding Down syndrome. Gergen (1999b) describes the dangers inherent in the solidification of any given way of constructing the world. He states:

> It is essential to set in motion processes of reflexive deliberation, processes which call attention to the historically and culturally situated character of the taken-for-granted world, which reflect on their potentials for suppression, and open a space for other dialogues of the culture….Reflexive deliberation has been, and continues to be, a significant form of scholarship within the constructionist frame. (p.5)

This thesis might be viewed then as reflexive deliberation focusing on what has been excluded from the dominant discourses regarding the experiences parents appreciate about parenting a child with Down syndrome from birth to adulthood.

Appreciative Inquiry

One application of social constructionist thought is "appreciative inquiry". Appreciative inquiry, according to Gergen (1982, 1990), treats social and psychological reality as a product of the moment, open to continuous reconstruction. Dr. G. R. Bushe (1995) of Simon Fraser University states that socio-rationalists (those who treat social and psychological reality as a product of the moment open to continuous reconstruction) argue that the theories we hold as a society, our beliefs about social systems, have a powerful organizing effect on the nature of social reality. "Not only do we see what we believe, but the very act of believing it creates it" (p.14). Cooperrider and Srivastva (1987) contend that looking at the problems in organizing and inquiry reduces the possibility of generating new images of social reality, new theory that might help transcend current social forms. Bushe (1995) asks the questions, "What if instead of seeing organizations as problems to be solved, we saw them as miracles to be appreciated? How would our methods of inquiry and our theories of organizing be different?"(p.15) Bushe states that in the past he focused on understanding the failures and pathologies of leadership and organization and now he focuses on helping people become aware of how good things are. From this stance he is finding that change happens more easily, people don't get so bogged down in despair. "The appreciative lens has opened up a new vista for viewing and understanding the process of change in human systems" (Bushe, 1995, p.15).

It is my choice to put on an appreciative lens rather than get bogged down in despair, and help generate new meanings and images of parenting a child with Down syndrome.

Construction of Disability

Biological Construction of Disability

Who defines and identifies individuals as disabled either physically or mentally? The World Health Organization attempted to universalize the category "disabled" under the *International Classification of Impairments, Disabilities and Handicaps* (WHO, 1980). Under the World Health Organization's classification system an impairment is defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (WHO, 1980, p.27). Impairment is defined "primarily by those qualified to judge physical and mental functioning according to generally accepted standards" (WHO, 1980, p.27). Impairments are disturbances at the level of the organ, which include defects or loss of limb, organ or other body structure, as well as defects or loss of mental function (UN, 1990, p.1). Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p.28). Handicap is defined by the WHO as "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for the individual" (p. 29).

This broad concept of disability was used in the Statistics Canada Health and Activity Limitation Survey (HALS) to develop an in-depth profile of people with disabilities in Canada (WHO, 1980). In British Columbia those labeled with a mental disability are categorized into three broad categories, the mentally challenged, the chronically mentally ill, and those with other mental health concerns (British Columbia

Premier's Forum, 1994, p.4). People with Down syndrome are categorized as mentally challenged because they are born with a permanent condition and the condition is present at all times throughout one's life.

Historical Construction of Disability

Negative views about the disabled date back to the dawning of Western Civilization. In Ancient Greece, often viewed as the cradle of civilization in the developed Western world, individuals with disabilities were lumped alongside other low lives and outcasts, namely slaves and women. Individuals with disabilities were considered "the private people", as opposed to the "public people", in Greek terms, they were "the idiots". However, the idiots held even less status than women or slaves. They were considered monsters, the lowest form of life. If they could be identified at birth, they were put to death (Stratford, 1991, p.5).

Attitudes in Europe during the Middle Ages continued to reflect rejection and intolerance of those considered to be disabled. The birth of a child with a disability was associated with sin on the part of the parents (Stratford, 1994). "Feeble minded" children were thought to be born as a result of a liaison with the devil and both they and their mothers should be burned at the stake. There was a well-established assumption that somehow evil was involved in the birth of these children (Stratford, 1991; Coleridge, 1993).

By the mid-1800s, physicians, psychologists, and medical scientists had come under the influence of a relatively new science known as statistics. These new scientists had a distinct way of looking at the world and at the people in it. Researchers looked at large numbers of people and tried to decide how to group them according to different characteristics. How to measure some of the more abstract human characteristics like intelligence was something considered worth studying. If there was such a thing as "general" intelligence, then it could be measured and people could be ranked according to their levels of intelligence (Goodey, 1991).

During this period, Francis Galton, cousin of Charles Darwin, was the first to assert that intelligence was a scientifically meaningful concept and that it was inheritable. He concentrated on developing new statistical and anthropometric techniques to measure intelligence (McLaren, 1990). In 1883, Galton asserted that the statistical approach, if used to encourage selective breeding, could solve the social ills that plagued Britain by developing enhanced humans. He graded and counted people according to their civic worth in the categories of desirable, passable, and undesirable and pushed for restricted breeding for the inmates in prisons, hospitals, and for the feeble-minded. Galton's "positive eugenics" was to encourage the fertility of the fit (McLaren, 1990).

Francis Galton's theory of eugenics had enormous appeal, not only in Britain but also in North America. In the United States by 1911, the American Breeders Association had been established to oversee the reduction of the mentally retarded population. By 1926, 23 states had made sterilization mandatory for any individuals considered mentally deficient. This resulted in the involuntary sterilization of over 60,000 individuals with mental retardation or illness by the year 1960 (Glover & Glover, 1996). In Canada as early as 1922, H. S. Patton, a University of Alberta economist noted that the rise of eugenics was a symptom of the new reign of professional experts who sought to control scientifically every situation. At the same time, Dr. Alexander Reid, superintendent for the Nova Scotia Hospital for the Insane, declared that the "ulcerous and diseased outgrowths on society" could not be permitted to reproduce (McLaren, 1990). Thus historically, in Britain, the United States and Canada, there were instances that suggest that persons with disabilities were not highly regarded but rather considered imperfections that contaminated the genetic stream.

Cultural Construction of Disability

To look at our present cultural construction of disability we must also look at the cultural construction of what it means to be "normal" for without looking at the construction of normal, the cultural construction of disability would be difficult to discuss. These two constructions seem to go hand in hand.

Everyday we are bombarded with information about what it means to be a normal human being. Despite the fact that human beings are refreshingly diverse in shape, size, color, texture, structure and functioning, both mentally and physically, modern commercial cultures construct the requirements of normality early in life. Anyone that deviates from these requirements is subject to much ridicule and biased treatment. Children are taught in our society to conform to standards in body size, carriage, movement, gesture, speech, emotional expression, appearance, scent, ways of eating, control of bodily functions such as salivation, passing gas, urination, and defecation. These standards are enforced by teasing, taunting and the threat of social ostracism (Wendell, 1996).

These disciplines of normality apply not only to the physical characteristics of human beings but to their mental capabilities, as well. Children learn that it is important to keep up, to perform academically at a certain standard or be subject to failure. There appears to be societal consensus that having a child labeled normal is significantly meaningful. Fletcher (1973) reflects this notion when he states that "a fetus with a severe defect has a lesser moral claim on the mother than a 'normal' child because he or she is less likely to respond to the promise of becoming a person in the community of persons" (p.672). Kliewer (1998) states that the social construction of the nature of children with disabilities produces a culture that, proportionate to their perceived defects, devalues them.

Goodey (1991) takes us back to the creation of conversations around the word normal, as we know it today. At the time large-scale institutions were being set up to segregate people labeled insane, the science of statistics was also taking hold. Medical science became enmeshed in the task of relegating how many people belonged to different groups according to intelligence. Tests were devised to measure how much intelligence one person had compared to someone else. Thus, there came to be a "common or normal intelligence" that was easier to measure. At first normal was a new word and meant something like average. However, since many of the groups categorized were considered inferior, this changed the perception of the word normal. Normal became a word constructed with a positive value attached to it. Normal intelligence became measurable with a value of superiority over everyone who was not considered normal.

Today, normal intelligence is measured by a variety of IQ tests and a score of 100 or thereabouts denotes the "average individual". IQ scores have become so important to some people that a low enough score can exclude a person from being considered human in their eyes. Lusthaus (1985) states that reaching a certain level of intelligence is one of the prerequisites for reaching a state of "humanness". However, Stratford (1991) states that although intelligence is often cited as the most important prerequisite for reaching this state of humanness, it "is the most difficult human characteristic to define. Too frequently we have to fall back on the measurement of IQ, the intelligent quotient, or how much one has of it in relation to how much of it one's neighbors have "(p. 7). Stratford suggests that IQ tests are a crude measurement of intelligence at the best of times. Nonetheless, IQ tests are still used as criteria for distinguishing between whom is considered normal and who is mentally disabled.

Current cultural constructions of disability appear to reflect our culture's aesthetic norms and preferences. In our highly competitive society certain human abilities and characteristics appear to be valued over others. Physical beauty, youth, virility, intelligence, and health, are all characteristics that are highly prized. Our society seems bent on producing "a perfect human being", the *Brave New World's* vision, referred to by Bjerklie, Dorfman, Gorman and Nash (1994). Blumberg (1994) states that people with disabilities have been objectified and no where is this objectification greater than in babies with disabilities. Babies that are labeled disabled are considered "defective" and labeled with such terms as "glaringly imperfect", "nature's mistakes" and "grossly malformed"(p. 137). According to Murphy (1995), who became disabled as an adult, our present cultural construction is one that says that the disabled, individually and as a group, contravene all the values of youth, virility, activity, and physical beauty that Americans cherish. Wendell (1996) regards this current level of cultural idealization, objectification, and quest for perfection as a collective sickness, an alienation from experience and reality. She questions who defines disability in our society, for what purpose, and with what consequences. Wendell states that we need an understanding of disability that contests the dominant discourse of humanity as young and healthy. Wendell states that disability has biological, social and experiential components and looks at the social construction of disability "through the failure or unwillingness to create ability among people who do not fit the physical and mental profile of paradigm citizens" (p.40). The cultural construction of disability is focused on weaknesses and inferiority rather than strengths and capabilities.

Murphy (1995) believes most people labeled as handicapped are subverters of the American ideal and as a result are interpreted by many people to be ugly and repulsive. Dahl (1993) exhibits how the media supports this construction. He states, "the mass media affects public opinion and public perception of social reality by their ability to create typifications"(p. 79). Children's classics are particularly graphic in their depictions of the villains as ugly and deformed while heroes and heroines are beautiful and graceful. Dahl suggests that Hollywood has tended to sentimentalize the disabled and film and television still often portray the disabled as helpless victims.

However, Ingstad and Whyte (1995) state the concept of disability itself must not be taken-for-granted as this concept has been culturally constructed. There are many cultures where "disability" is not a recognized category. They state that the WHO's attempt to universalize the definition of disability creates many problems. The concept of disability and how it has been constructed in Euro-American, Western society is different than the way other cultures understand this concept and a fundamental theme underlying our definition of disability is the assumption of the desirability of equality, understood as sameness or similarity (p. 7). In our society physical or mental differences are oftentimes viewed as disability and Wendell (1996) suggests that in an ideal setting people with disabilities might be viewed as valuable for their different knowledge, perspective and experience instead of being pitied, patronized, or shunned. Disability rights activists and scholars alike are now focusing on the social processes that construct handicap not so much in terms of people with impairments, but as outcomes of society's discriminatory practices (Anderson & Bury 1988; Williams, 1989). If there was more acceptance of differences and not such a strong striving for what is considered normal in our society, Down syndrome might not be considered a disability but just another way of being in the world.

Construction of Down syndrome

Biological Construction of Down syndrome

Down syndrome occurs in all parts of the world, irrespective of race, creed, color, climate, or economic status, with an overall incidence of approximately one in 700 to 1000 live births (Trumble, personal communication, April, 1997; Stratford, 1994; Steele, 1996). The exact cause of Down syndrome is still unknown. However, the biological mechanism by which Down syndrome occurs is now understood. All people with Down syndrome have an extra, critical portion of the number 21 chromosome present in all, or some of their cells. This genetic alteration occurs at or around the moment of conception. The additional genetic material, in the form of extra genes along the twenty-first chromosome, alters the course of development and causes the characteristics associated with the syndrome. (See Appendix A for further information on the biological definition of Down syndrome.)

The most well known characteristic associated with Down syndrome is "mental retardation". (See Appendix B for more detailed definitions of mental retardation and developmental disability). The National Down Syndrome Society states that Down syndrome accounts for one third of all cases of mental retardation (personal communication, November 25, 1996).

Historical Construction of Down syndrome

Individuals with Down syndrome do not constitute a new presence in this world. For centuries, people with Down syndrome have been alluded to in literature, science and art (National Down Syndrome Society, personal communication, November 25, 1996). Historically, people with Down syndrome in the developed, Western world have been judged harshly. Stratford (1996) states that in European society, handicapped people were lucky to survive at all. People with Down syndrome were easy to pick out as different and therefore easy targets as patients for the first institutions that were developed in the 1800s for those considered mentally defective.

Britain's first large-scale institution to segregate and incarcerate the "idiots" and "the insane" or people considered mentally defective came in the mid-1800s along with the development of eugenics. The chief physician at this new institution was a Dr. John Langdon Down. He had devoted himself to the treatment of the mentally deficient even though the common train of thought was that nothing could be done for these types of people (Goodey, 1991). Esquirol, considered to be the father of psychiatry, summed up the thinking of the time: "It is useless to combat idiocy. In order to establish intellectual activity, it would be necessary to change the conformation of the organs which are beyond reach of all modification" (Stratford, 1994, p.5).

Disregarding his colleagues, Dr. Down pooled the old emphasis on physical appearance together with the new ideas of statistics and intelligence. He developed a theory that some people at the lower end of the intelligence scale might have a different physical appearance from the rest. He found that there was a group of people in this large institution that he labeled "Mongols" because of what he considered to be their Mongolian type facial similarities; for example, their almond shaped eyes. Down appeared to regard the retarded as evolutionary throwbacks or "atavistic regressions" to inferior races, hence his "ethnic classification of idiots" (Clarke & Clarke, 1996). Ethnicity was an accepted cause of mental deficiency during this time and the further away from London one lived, the more primitive one became (Goodey, 1991). To use the label "mongoloids" fit well with Down's construction. By the turn of the century, the condition Down had labeled as "mongoloid idiocy" was now also being referred to as Down syndrome. Throughout the 20th century, advances in medicine and science enabled researchers to continue the study Down had begun. In 1959, the French physician, Jerome Lejeune, identified Down syndrome as a chromosomal anomaly. Instead of the usual 46 chromosomes present in each cell, Lejeune discovered 47 in the cells of individuals with Down syndrome (Stratford, 1994).

Cultural Construction of Down syndrome

Since the first medical description of Down syndrome put forth by Dr. Langdon Down in the last century, there has been a vast amount of research and knowledge accumulated about Down syndrome. Down syndrome has become dominantly portrayed in medical terms used to describe a chromosomal anomaly or a genetic disease that causes intellectual delays and physical irregularities. Foucault (1977) has suggested:

> there is a close relationship between language (including all forms of text) and social process (conceived in terms of power relations). In particular, as various professions (e.g. the sciences, government, religion, and the courts) develop languages that both justifies their existence and articulates the social world, and as these languages are placed into practice, so do individuals come under the sway of such professions. (p.102)

The primary development of historical and cultural forms of discourse about Down syndrome have taken place in medical and scientific circles and created language that articulates Down syndrome predominantly in biomedical terminology. There is no disputing the biological differences in someone labeled with Down syndrome and medical terminology has been dominantly used to discuss these variances for more than 100 years. However, this powerful, bio-medical discourse about Down syndrome has emphasized pathology and abnormality and has created the cultural constructions we know today. Kliewer (1998) identifies what he calls the "commutative law of Down syndrome: mental retardation and Down syndrome are held to be one and the same; name one and it is the same as the other"(p.50).

The dominantly negative depictions of Down syndrome continue to be perpetuated with bio-medical descriptions. Down syndrome is still discussed in genetic texts as, "An important and tragic instance of trisomy in humans involves Down's syndrome, or mongoloid idiocy" (Berube, 1996, p. 25). In medical journals the focus is often on health complications:

> Down syndrome…is the commonest cause of mental retardation and is also associated with major structural anomalies of the heart and gastrointestinal system and an increased risk of leukemia. Early mortality is high, mainly due to congenital heart defects…Most surviving adults go on to develop brain abnormalities that are typical of Alzheimer's disease. (Williams, 1995, p.47)

These accounts illustrate the medical dialogue used to describe a person with Down syndrome. With our society's strong drive for normalcy and perfection, many people, including health professionals, have come under the sway of this medical language. Focused on terms that describe health complications and intellectual delays, these dominant discourses on Down syndrome have articulated our social world and focused individuals on the medical label of Down syndrome.

Along with these dominantly negative medical articulations of Down syndrome, comes the perspective that having a child with Down syndrome is a drain on resources. Stein, Susser and Guterman (1973), Sadovnick & Baird (1981), Conley (1985), Hook (1994), and Kupperman, Golberg, Naese, and Washington (1999) have done studies that focus on the economic analysis of raising a child with Down syndrome versus prenatal testing and abortion costs. These researchers express concern about the burden that caring for someone with Down syndrome puts on the medical delivery systems. They conclude that prenatal identification of a child with Down syndrome is economically attractive. Pueschel (1991) explains that these "cost-benefit studies often indicate that society would save money if fetuses with Down syndrome would be selectively aborted"(p.189). With the prevailing discourse focusing on the medical problems, complications and financial burden of Down syndrome, the current focus on prenatal detection and prevention appears reasonable and irrefutable.

With the availability of genetic testing, the diagnosis of chromosomic abnormalities, specifically Down syndrome, has become common place in our society. Prenatal diagnostic techniques have slipped almost unnoticed into routine obstetric care with little public scrutiny or debate (McDonough, 1990). Kolker and Burke (1993) state that as prenatal screening for fetal abnormalities has become safer and cheaper, its use has grown. Prenatal screening specifically for Down syndrome is now part of regular prenatal care. Blumberg (1994) states that "prenatal testing has become entrenched in American culture" (p. 136).

Because the risk of Down syndrome increases with advancing maternal age, policies to offer amniocentesis and chorionic villus sampling (CVS) (see Appendix C) have generally focused on women who are at least 35 years at the time of delivery. However, with the current expansion of maternal serum screening programs, prenatal detection of genetic abnormalities is becoming accessible for pregnant women of all ages

(Kupperman, Golberg, Nease, & Washington, 1999). Elkins and Brown (1995) state that in an effort to separate mild and serious anomalies, Down syndrome was the only nonlethal anomaly listed among serious anomalies found by genetic testing in the largest screening program in the United States. The first universal screening effort for a single disorder with a non-lethal prognosis came after the recommendation by the American College of Obstetricians and Gynecologists that every pregnant woman in the United States be offered a triple screen for Down syndrome. Currently in BC, all pregnant women, regardless of their age are offered the triple marker screen. If the screen is returned with positive results, these women then have the choice of a more conclusive test for Down syndrome.

This focus on prenatal detection is the subject of a study done by McDonough (1990), who reviewed 104 empirical studies (published between 1967 and 1987) in leading medical journals affiliated with the major Canadian, British and American medical associations. McDonough found that prenatal diagnosis was considered to be a desirable course of action to promote the births of "normal, healthy" children. Social striving for the birth of a healthy fetus versus a fetus considered to have a disability, defect, or impairment is strongly supported in the literature (Glover & Glover 1996; Blendon, Benson, & Donelan, 1993; Botkin 1995; Blumberg, 1994). Botkin (1995) reports that the prerogative of using prenatal screening and selective abortion to avoid the birth of an impaired child has been widely accepted in our society and for the past twenty years 79% of the U.S. public had supported abortion in the case of serious fetal defect. Abortion is not only largely supported by the general public for what is judged to be serious fetal defects, but also appears to be strongly supported by the medical profession. Williams (1995) states that there is still a presumption among doctors that all Down syndrome pregnancies that are detected will be terminated (p.47).

To date, there are no specific regional or national statistics regarding the incidence of elective abortion following the prenatal diagnosis of Down syndrome. However, Palmer, Spencer, Kushnick, Wiley, and Boyer (1993), Blumberg (1994), Berube (1996), and Glover and Glover (1996), state that most women faced with the diagnosis of Down syndrome choose to terminate the pregnancy. Steele (1996) states, "Clearly, no one would wish a child to be affected by Down's syndrome and developments in prenatal diagnosis enable parents to exercise much greater choice now" (p.54). The desire for normal, healthy babies and the prevailing negative bio-medical depictions of Down syndrome have helped create the scenario where given a choice, the majority of women will not bring a fetus with Down syndrome into the world. I suggest that women's choices are strongly influenced by our historical and cultural constructions of Down syndrome and parenting a child with Down syndrome and that within our society these constructions have become solidified. With these solidified constructions, it is difficult to see someone with Down syndrome as a unique person. However, Gergen (1999b) reminds us that there are critical dangers in holding on to any given way of constructing the world. Centuries of labeling, categorization, and different degrees of persecution of people with Down syndrome has moved us as a society towards collective agreements on what is real, rational, and right about Down syndrome and we have articulated these agreements in forms of language. The dominant articulations depict a person with Down syndrome as the "disease", where the individual with Down syndrome's personhood is forgotten. Kleiwer (1998) comments on the physical differences of someone with Down syndrome and how it is not the differences that are important here but the meanings our society has attached to these differences:

> Though these genetic and physical differences are a reality outside and apart from our interpretative processes, it is the meaning we attach to the differences, the cultural constructions, that turn them into the ones that matter when establishing an understanding of Down syndrome. (p.17)

Under the sway of these dominant cultural constructions and with increasingly refined and more available prenatal testing, growing numbers of prospective parents are faced with difficult dilemmas when they are told they have a fetus that may potentially have Down syndrome. Given the prevailing socially constructed messages about Down syndrome that focus on medical problems and burden, the junction point where health professionals share information about Down syndrome with prospective parents is critical. Into these counselling sessions, parents and health professionals bring different values, prior experiences and knowledge bases. As counselors provide information, parents integrate that information with what they already know, their personal values and experiences and project into the future. Parents make momentous life and death decisions during this relatively brief, pre-birth reflection time. Kolker and Burke (1993) state real life decisions on prenatal options "is a complex, subjective process, fraught with emotion and embedded in life experiences and socially constructed messages"(p.52).

Most parents want the best for their children. White (1999) states factors that influence reproductive decisions are parenting values that include parents' concern for the best interests of their children, parents' desire to minimize their children's suffering and their expectation of some type of rewarding relationship with their children. Currently, when prospective parents receive a positive screening result for Down syndrome, concerns and fears about the fate of that child, what the future will bring and how they might cope as parents are constrained by the prevailing discourses on Down syndrome. At this critical decision making time, health professionals involved in genetic counselling (medical professionals, genetic counselors, or counselors) play a crucial role in helping parents make informed decisions by providing a balance of information about Down syndrome. This information needs to include not only the medical issues regarding Down syndrome, but also what it might be like to share one's life with a person with Down syndrome. Regardless of whether parents finally decide to abort the fetus or continue with the pregnancy, the critical issue is that parents' decisions are well informed.

The Role of Long-term Caregiver

As prospective parents reflect on parenting a child with Down syndrome, one of the concerns that may arise is what will happen as their child gets older and enters adulthood. Prospective parents are faced with the idea that their child may not ever live independently. The idea of giving care to or being caregivers for adult children with developmental disabilities is described by Cantor (1983) as at least a two-person dyad, the person receiving assistance - the care-receiver, and the individual providing care - the caregiver. Caregiving has been referred to as "a life long task" (Roberto, 1993, p.7) or "perpetual parenthood" (Jennings, 1987, p.430). With the rising numbers of children with Down syndrome living to adulthood, the role of long-term caregiver becomes more of an issue for prospective parents.

With improved health care services, many children with Down syndrome are now living well into their adult years. In 1932 the mean survival age for a person with Down syndrome was nine years of age (National Down Syndrome Society personal communication, November 25, 1996). Concerns that would have proved fatal for a person with Down syndrome in the past are no longer life threatening. Today 80% of persons with Down syndrome can expect to reach age 55. Furthermore, improved health care has also lengthened survival of parents and many parents of children with Down syndrome are now caregivers well into their senior years. Seltzer, Krauss and Tsuenmatsu (1993) state that across all ages fewer than 20 percent of those with mental retardation live in a licensed residential setting. With more than 80 percent of adult children labeled with mental retardation still at home, elderly parents remain the major resource and support for these adult children (Jennings, 1987; Roberto, 1993). Currently, parents are the main caregivers for their children with Down syndrome throughout their lives.

Because there is very little research done with caregivers of adult children with developmental disabilities, more research is being called for in this area. Jennings (1987) wants the focus of caregiving research to be on the "nature of caregivers' stresses and service needs" (p.432). She describes some of the problems long-term caregivers face as they age and their own health becomes increasingly fragile. Jennings states that these caregivers struggle with isolation, loneliness, fatigue, inadequate support from community resources, excessive strain on family finances, role overload, change and adjustment of lifestyles, and feelings of burden. Certainly, it is important to be aware of, and acknowledge these caregivers' struggles and concerns and more research needs to be done in this area. Prospective parents need to know about the challenges of caregiving in order to make informed decisions and to learn that caregiving involves a full spectrum of experiences.

An Appreciative Lens

Roberto (1993) states that very little has been written about caregivers of adults with developmental disabilities and that negative aspects of caregiving predominate the research in this area. However, more studies are beginning to focus on the rewards of parenting a child with Down syndrome and the role the parent takes on as caregiver is not one that is totally consumed with burden. Studies by Grant (1986), Gath (1985), Elkins, Stovall, Wilroy, & Dacus, (1986), Pueschel (1991), Cunningham (1998), and Van Riper (1999), all suggest there are experiences parents appreciate raising a child with Down syndrome from birth to adulthood. Grant (1986) suggests caregiving of mentally handicapped adults is not just a burdensome association for the caregiver but also serves as a relationship that may provide reciprocity of care and companionship. In his study on older caregivers, regarding their interdependence with the care of mentally handicapped adults, he found that there were strong bonds of mutual aid between some caregivers and their dependents, caregiving was not unidirectional. Moreover, Grant states that it would be wrong to assume that old age brings nothing for caregivers but social euthanasia. He discovered that one tactic deployed by lone caregivers was to extract every ounce of satisfaction and reward from the process of caring. He suggested that this meant that caregiving roles could become partly reversed, and that the traditional dependency relationship pictured so often, really resembled more of an interdependence between the carer and cared for (p.336). Grant's research suggests that there is more to long-term caregiving than stress and burden.

Pueshel (1991) notes that today the majority of individuals with Down syndrome are not institutionalized and become productive citizens rather than what some would consider burdens to society. Gath (1985) has concluded that when things go wrong for a family, the fact that they have a child with Down syndrome often leads people to believe that problems will be the inevitable results of the increased stress associated with raising a child with Down syndrome. However, she found that many families of children with Down syndrome are able to function in a healthy way and a notable number of families have found their lives were enhanced by what they originally thought was going to be an unbearable burden. Elkins, Stovall, Wilroy, & Dacus (1986) surveyed 101, predominantly white, middle income families. They found that over 70% of mothers of children with Down syndrome indicated that their marriage and family had been brought closer together as a result of having a child with Down syndrome, and 84% stated the experience had been rewarding overall (p.192).

Cunningham (1998) began one of the largest and most detailed multifactorial programs of research ever done in this area in 1973 with 183 families of children with Down syndrome. Today over 100 families still remain in the study. This study concluded that the predominant impression of families and their child with Down syndrome is one of normality. The factors that influenced the well being of members of each family in the study were similar to those influencing any child or family. The majority of families exhibited no pathology as a consequence of having a child with Down syndrome, but rather the evidence pointed to positive effects for many families when one member has Down syndrome. Van Riper (1999) has conducted six studies about the family experience of living with Down syndrome and her findings to date indicate that "while the birth of a child with Down syndrome involves a 'change of plans' for families, it does not have to be a negative experience. In fact, for many families, it is a positive, growth producing experience" (p.3). Van Riper is calling for more research that shifts the focus from assessing stress and distress, to assessing resilience and adaptation with regards to parenting a child with Down syndrome.

As well, first hand experiences have been shared about parental experiences that challenge the dominant constructions of Down syndrome. Over thirty years ago, Nigel Hunt, a young man with Down syndrome authored the first book ever written by an individual with Down syndrome. His parents had been told many years earlier, that no matter how much trouble they went to, no matter how much love and care they gave Nigel, he would be an idiot and there was nothing they could do to alter that fact (Hunt, 1967). Other parents have been told to institutionalize their children with Down syndrome and instead kept their children at home, loved and supported them, and have gone on to see their children graduate from high school, author books and/or become actors. (Kingsley & Levitz, 1994). It is becoming apparent that there is now academic literature available that is beginning to challenge some of the dominant constructions of Down syndrome.

Providing Balanced Information

As multiple genetic tests become increasingly available, clinicians face challenges in providing a broad base of information to prospective parents so that they understand the nature of the tests, the results and the options available. White (1999) implies the significance of a consultation with persons or resources that can be counted on to provide prospective parents with a variety of viewpoints:

> We make most of our important decisions following consultation with others both within and beyond our immediate communities; perhaps an expert, a trusted friend, or an authoritative text – in any case, persons or resources that can be counted on to provide additional considerations or perspectives…through dialogue with an informed partner, the understanding and perception of one's alternatives may be increased. (p.17)

The conversations between prospective parents and a health professional during these counselling sessions have the potential of increasing the parents' understanding and perceptions of alternatives. Burke & Kolker (1994) state that genetic counselors now play a vital role in helping parents make informed decisions regarding prenatal testing.

However, Williams (1995) states that currently, "concern has been expressed that the information and advice given to parents at the time of these (prenatal) decisions is overly negative"(p. 46). A number of researchers agree that prospective parents need to be provided with more extensive information and greater opportunities for counselling and support. (Pueschel, 1991; Spudich, 1992; Statham and Green, 1993; Blumberg, 1994; Elkins, Stovall, Wilroy, and Dacus, 1986; Stein 1997; and Helm, Miranda, and Chedd, 1998). Blumberg (1994) states that the advice genetic counselors give to prospective parents may be inevitably distorted because they see disabled persons largely in medical settings where the focus is on the individual's dysfunction. At a conference held by the International League of Societies for Persons with Mental Handicaps on Bioethical Issues in Canada in 1992 it was concluded that professionals involved in prenatal diagnosis and counselling know frighteningly little about the lives of persons with Down syndrome, about new developments in education and training and about the reasons for a positive outlook. Worse, they may not even know anyone affected by Down syndrome. The conference delegates determined that information provided by health professionals during prenatal diagnosis should not merely consist of medical facts, but should draw a fuller picture of what can be done to make life meaningful for persons with Down syndrome (Spudich, 1992). Drawing this fuller picture of a person with Down syndrome is one of the biggest challenges health professionals face in their counselling sessions with prospective parents.

In the study done by Helm et al. (1998) ten mothers who had decided to keep their babies with Down syndrome had several recommendations for medical professionals who work with parents undergoing prenatal testing. Some of the advice they offered was:

> Make sure parents understand all prenatal tests....Do not make assumptions about the parents' decision....Do not make judgements about the parents'

> decision....Give nonjudgemental information on all three options: continuation of the pregnancy and parenting, continuation of the pregnancy and adoption placement, and termination of pregnancy....Give up-to-date printed material on Down syndrome....Make referrals to Down syndrome programs....Do not accentuate the negative....Do not use negative terminology. (p.59)

Asch & Fine (1988) propose that the more information a woman has about the real lives of disabled children and adults, rather than simply abstract medical conceptions about "prognosis", the less likely her decision will be based on fear and repugnance towards persons with disabilities. However, in our society where the "official medically-dominated" constructions are that Down syndrome is an "abnormality" or "error of nature" (Williams, 1995, p. 48), health professionals are faced with the challenge of somehow imparting to prospective parents different information about Down syndrome. Pueschel (1991) suggests how paramount it is for genetic counselors to sensitively provide the positive aspects of caring for a child with Down syndrome. He states that factual information, various options and guidance are essential components of these counselling sessions, in order for prospective parents to make independent, informed decisions. Saxton, Anderson and Blatt (1991) state what is lacking is information and guidelines on how to support parents who choose to continue with a pregnancy. Finnegan (1991) states that information is also lacking for parents deciding to make adoption plans. Kolker & Burke (1993) agree that couples undergoing prenatal diagnosis deserve more complete information about the consequences of alternative procedures so they can make truly informed decisions. Helm et al.(1998) states that the mothers in their study did not want their information "sugar- coated"(p.61). However, they wanted health professionals to provide current, up-to-date information about all options and to do so in language that was both understandable and not focused on the negative.

The importance of a comprehensive, thorough discussion with prospective parents regarding Down syndrome with a balance of information and options becomes even more significant when the emotional state of the parents is considered during this prenatal testing time. Pueschel (1991) states that when parents are confronted with the diagnosis of a fetus with Down syndrome, they frequently display impaired decision making capacity and they are exceptionally vulnerable. Palmer et al. (1993) agree that prospective parents are often still in the state of shock when life and death decisions must be made and time constraints are an issue because such decisions must be made rapidly. In the study done by Helm et al. (1998) prospective mothers who had had positive diagnoses for Down syndrome made these recommendations for other mothers facing similar situations:

> Take as much time as you can in making your decision, try not to feel rushed or pressured by others' opinions. Consider the positive and negative aspects of all options. If you decide to continue the pregnancy, then talk to parents of different ages with Down syndrome....Gather as much information and resources as you can. (p.60)

Berube (1996), a parent of a son with Down syndrome, gives a description of what he considers the ideal prenatal testing setting. Upon learning that their unborn child has Down syndrome, prospective parents would be given all the relevant medical prognoses about possible health risks and at the same time they would be offered testimonies from various families, both parents and siblings, as well as from people with Down syndrome themselves. With this type of information, parents could make informed decisions knowing that people with Down syndrome are individuals like anyone else and with every individual comes a variety of joys, sorrows, and challenges.

Blumberg (1994) suggests that the greatest failure of conventional genetic counselling is that couples are rarely encouraged to meet with disabled persons or their parents. In the study done by Helm et al. (1998), mothers described meetings or phone calls with parents who already had children with Down syndrome as being tremendous sources of support and information. These mothers said that these conversations with other parents were the single most important connection they made during the prenatal period.

The prenatal counselling session that Berube (1996) describes is conceivable. However, in order for this counselling setting to become a reality, parents' voices are an essential ingredient. Goodey (1991) states that parents' voices are not often heard in the existing academic and professional literature on the subject of raising a child with Down syndrome, in the media or anywhere else. Although there is an increasing amount of recent research about enhanced family environments related to having a child with Down syndrome in the family, parents' voices are lacking. In order to address this issue, Goodey (1991) interviewed and then transcribed conversations with eighteen families who had a child with Down syndrome between the ages of two and eight years. He did not try to interpret but simply published selected extracts to reveal what the parents had to say. One parent in Goodey's study summed up the significance of parents' voices being heard when she stated, "I don't think they understand, doctors; I can't see how they can, and like the only people that really understand are the ones that have the children"(p.135). The transcripts provided by Goodey are largely appreciative.

In this study, documenting experiences parents appreciate with adult children with Down syndrome may add more configurations to limited traditional imaginings because of the longer time spent by parents with their "adult" child. Parents' voices are an essential part of balanced information for prospective parents, as they alone really understand the joys, sorrows, and challenges of parenting a child with Down syndrome. Parents can share these experiences like no one else is able to do.

Reason for this Research Question

With the steady increase and sophistication in genetic testing, there are continually increasing numbers of critical life and death decisions that are being made by prospective parents about fetuses with Down syndrome. Kolker and Burke (1993) suggest that in real life, reproductive decisions are neither rational nor simple. They state that decisions about prenatal diagnosis are socially constructed in accordance with the parents' experiences, needs, and meanings. The decisions made reflect the parents' backgrounds, the dynamics of the counselling session and subjective perceptions of the different outcomes.

It is not the intent of this research to judge these decisions. Every genetic decision will be based on multiple factors and the unique characteristics of each parent's situation. Each individual will respond to the information provided by the health professional in the context of her/his personal understandings and circumstances. However, the information provided during these brief encounters between health professional and prospective parents is becoming an increasingly decisive factor in this critical decision making process. Research to date implies that the information made available during this meeting time is skewed to the negative because of the longstanding dominant forms of discourse on Down syndrome.

This research offers an opportunity to share the rarely considered appreciative experiences of parents of adult children with Down syndrome. Looking through an appreciative lens, this research expands on the current dominant forms of discourse on Down syndrome and what it might be like to parent a child with Down syndrome and thereby challenges the primacy of these dominant forms of discourse. The findings from this research are based on the voices of parents that took part in this study and the meanings and images constructed as we dialogued together. These findings are intended to add an appreciative breadth to factors considered by prospective parents of children with Down syndrome, and the health care professionals that assist them, in making decisions about the future of fetuses with Down syndrome.

Chapter 3

Methodology

This study regards prevailing views on Down syndrome and parenting a child with Down syndrome, as dominant cultural constructions. After reviewing the development of biomedical, historical, and cultural forms of discourse about Down syndrome, and parenting children with Down syndrome, I chose to have conversations with parents and focus on their appreciative experiences of parenting adult children with Down syndrome. I wanted to offer other options to the taken-for-granted patterns and engrained forms of existing discourse about Down syndrome and parenting a child with Down syndrome. My research question gives voice to another cultural enclave, one that includes appreciated experiences about parenting an adult child with Down syndrome: What experiences are appreciated by primary parent caregivers living with a person with Down syndrome from birth to adulthood?

Because I come from a constructionist perspective, I am part of this study's constructions of appreciation. I have helped create the concepts of appreciation developed in this study through my choice of topic, my assumptions, my questions, and my choice of method and analysis. Together in conversations, the participants and I created the concepts of appreciation to be shared in this study. It is important to remember that as a constructionist, I believe that we create meanings together in dialogue. The concepts of appreciation were not something I discovered as I did this research, but something the participants and I built together.

Theoretical Underpinnings for the Approach Used

Until recently, as Plager (1994) notes, research has been deeply entrenched in a world view that focuses on the Cartesian model of inquiry on which most of modern science and research is based. The Cartesian model has also been commonly referred to as the scientific paradigm or as the rationalistic paradigm by Guba and Lincoln (1982). This model or paradigm of inquiry abstracts and generalizes so that there is a disengagement from our world through the process of objectifying it (pp.67-68). Axioms of this paradigm include that there is one single reality and that the inquirer remains independent and objective. Every action can be explained as the result of a real cause or causes. The best method for establishing cause-effect relationships is the experiment that demonstrates via manipulation that introducing the cause(s) produces the effect, and context-free generalizations are made based on similarities (Guba and Lincoln, 1982, pp. 236-238).

Guba and Lincoln (1982) propose that the naturalistic paradigm has recently emerged as a serious contributor in social/behavioural inquiry as it is a paradigm that can "tolerate real world conditions" (p.234). They describe interactions between humans as multilayered and complex and language as multidimensional as it is used in different contexts. The naturalistic paradigm fits with my constructionist perspective. It enables me as the researcher to cope with actual world conditions rather than manipulating those conditions to meet the design requirements of a more rationalistic paradigm. Therefore, the naturalistic paradigm was used to guide this study, as it is the paradigm that fits with a constructionist perspective.

There are five axioms outlined by Guba and Lincoln (1982) that describe the naturalistic paradigm and they will be examined in relation to social constructionist theory and the area of inquiry to illustrate the fit. The first axiom states that there are multiple, intangible realities constructed by people that can be studied holistically. From a constructionist perspective, people interpret and construct reality based on their experiences and interactions. We construct our meanings, our realities, our truths, as we relate to one another and yet meanings, realities, truths, are continually negotiated until we find something that works for us. Each caregiver has had different experiences; each parent creates his/her own reality as he/she interacts with his/her child and others.

The second axiom states that there is mutual interaction between the inquirer and the respondent. Guba and Lincoln (1982, p.239) believe that it is impossible to abandon one's humanness when doing research. They state that the inquirer and other human beings, or the participants interact to influence one another. During the interviews, the participants and I turned to each other in language and constructed our meanings of appreciation together. I interacted with the participants and used conversation to negotiate shared meanings of appreciating their adult children with Down syndrome.

The third axiom recognizes that generalizations are impossible since phenomena are neither time nor context free. The naturalistic paradigm recognizes that in the social/behavioural sciences, "the truth" at one time and in one context may change to a different truth in another time and context. Differences are as interesting as similarities. From a constructionist's perspective, it is very difficult to accept any particular solidification of the world, as meanings, truth, realities, are continually negotiable.

Guba and Lincoln (1982) recognize that in the naturalistic paradigm human behaviour is context bound. Therefore, in my study, although there may be some measure of generalizability from one parent context to another, situations and contexts are understood to be different. To generalize is not a goal of this research. As an inquirer coming from naturalistic and constructionist perspectives, I am not concerned with creating some truth about certain aspects of parenting.

The fourth axiom states that "all entities are in a state of mutual simultaneous shaping so that it is impossible to distinguish cause from effects" (Lincoln & Guba, 1985, p.38). Inquirers can only establish plausible inferences about the patterns in any given action and is best done in the field in a holistic, natural context. There can be no certain way of determining a cause-effect relationship. The aim of this research is to focus on the rarely considered experiences parents appreciate about having an adult child with Down syndrome, not to isolate a cause-effect relationship.

The fifth axiom is that inquiry is always value bound. Naturalists presuppose that inquiry is based on the value systems that characterize the inquirer, the respondent, the paradigm chosen, the methods selected, and the social and conceptual contexts. "Anyone who has done research involving humans is well aware that one cannot abandon one's own humanness in the interest of 'objective' inquiry; it is impossible and ethically undesirable to do so" (Guba & Lincoln, 1982, p.240). A rationalistic paradigm, where the inquirer attempts to remain value free, independent, and objective is not possible or desirable according to Guba and Lincoln. As the researcher I have exposed and explicated my values so the reader knows where I am coming from as the inquirer. Using constructionist theory, I consider myself a part of the construction of the concepts and meanings of appreciation that come out of this research. I am not a discoverer, but a builder in conversations with my participants.

There was little question that a qualitative research design fit with my constructionist stance and with the phenomenon that I wanted to study. Using in depth interviews, I allowed parents to share their experiences more fully and facilitated the negotiation of new meanings together. As a researcher, it was important to me to communicate clearly what I had done. Therefore, I documented my method of research explicitly. According to Gilgan (1993), the fit of the qualitative approach to the research study is critical for serious and valuable results:

> Qualitative approaches are about ideas: discovering them, developing them, and communicating them....We cannot assume readers will understand what we are doing. We not only must do our research well and write it up in ways faithful to what we have found, but we have a special burden of explaining to others what we have done, why we have done our work the way we did, and why ideas supported by words and not numbers can be serious and yield valuable results....The burden is on us to figure out and communicate what we did. (p.179)

Method

I chose some of van Manen's (1997) research activities to use in my study because they provided salient guidelines for a beginning researcher. Plager (1994) states that as one gains skill and alacrity in interpretive work, that the need for models, canons, guidelines and rules falls away. However, as a beginning researcher, I used these guidelines and others to help me stay focused:

- Turning to a phenomenon that seriously interests the researcher and commits him or her to the world.
- Reflecting on the essential themes that characterize the phenomenon.
- Describing the phenomenon through writing and rewriting.
- Balancing the research context by considering parts and whole. (pp.30-31)

Dimensions of the Sample

I began my research in January 1999 when I made initial contact with potential participants. The sampling procedure used in this research is known as purposive sampling. Palys (1992) describes this procedure as one that does not aim at "representativeness" (p. 146). The criterion for inclusion in this study included being a primary parent caregiver and having a child with Down syndrome over the age of eighteen. I enlisted the help of two people who work with adults with Down syndrome who intentionally sought parents who met the criterion for inclusion in the study. They gave me names of six families who resided in either Prince George or Comox.

Of these six families, all six mothers agreed to be part of the study. However, three of the mothers wanted to include their spouses in the interviews. One mother stated that both she and her husband contributed equally to the caregiving and therefore she could not stipulate who the main caregiver was. The other two mothers stated that although they were the main caregivers, the fathers still wanted to contribute to the interviews. Both fathers in these two cases had been involved in many aspects of the caregiving especially after retirement. In the end there were six families with a total of nine parents, six mothers and three fathers who took part in this study. The children with Down syndrome had no part of the conversations in this study. (See Appendix D, Dimensions of the Sample)

Potential participants were contacted by phone. Upon confirmation of interest in participating in the research, I arranged an interview time and date. Before being interviewed, each participant was sent a letter of introduction outlining the purpose of my research and a consent form. (See Appendix E) Confidentiality and the voluntary nature of their participation were emphasized. I had a short briefing session before each interview to make sure that the participants understood the context of the study and were comfortable with the use of the tape recorder. Any questions that the participant had were answered at this time. Once the consent form was signed, an identifying code number was given to each participant that identified him or her throughout the rest of the study.

The research consisted of a total of twelve interviews; six initial interviews and six follow up interviews. A block of time lasting from one to two hours was allocated for each initial interview. All the interviews took place in the participants' homes except for one set of interviews, which took place in my home at the participant's request. Each parent or set of parents was interviewed two times, the initial interview and then a second interview to check out my interpretations. Each interview took an average of one to two hours to complete.

Data Collection

In this study the interviews were used as a way of dialoguing with parents through an appreciative lens. The initial interview explored the experiences caregivers appreciated about parenting a child with Down syndrome from birth to adulthood and each caregiver was asked to describe and elaborate on these experiences. van Manen (1990) states that for interviewing:

> …it may be helpful to be very concrete. Ask the person to think of a specific instance, situation, person, or event. Then explore the whole experience to the fullest….And whenever it seems that the person being interviewed begins to generalize about the experience, you can insert a question that turns the discourse back to the level of concrete experience. (pp.67- 68)

I attempted to converse about concrete experiences and establish an atmosphere where the participant felt safe enough to talk freely about her or his experiences and feelings. I tried to encourage the parents to explore their experiences and no participant was stopped from sharing if the interview went a little longer than expected.

I used the questions and probes provided in the interview guide (Appendix F) to help facilitate the discussion around what parents appreciated about the experiences of parenting a child with Down syndrome from birth to adulthood. Underpinning each of the interview conversations was the fundamental research question.

At the end of each interview I followed a debriefing procedure. Kvale (1996) states that the subject may be tense or emotional after such personal sharing and it is important to close with some debriefing time. I found that once the tape recorder was turned off, the participants continued to share and ask questions for at least fifteen minutes.

After I had completed each interview and left the participant's home, I took fifteen to thirty minutes of quiet time to reflect on each interview and kept a journal about immediate impressions, recalling any pertinent information not captured by the tape recorder. This was done to provide what Kvale (1996) calls a valuable context for the later analysis of the transcripts. It is important, according to Krefting (1991) that the researcher utilizes reflexivity in order to evaluate the influence of the researcher's background and constructions on the research study. Therefore, my background and assumptions were noted before the research began and ongoing field notes were kept during data collection and analysis as an important supplement to other data collecting methods. All data was considered valuable. Bogdan and Biklen (1982) state:

> the tape recorder misses the sights, the smells, the impressions, and the extra remarks said before and after the interview. Fieldnotes can provide any study with a personal log that helps the researcher to keep track of the development of the project, to visualize how the research plan has been affected by the data collected, and to remain self-conscious of how he or she has been influenced by the data. (p.107)

One of the things I noted upon reading my reflections was the importance of non-verbal communication. There were situations that transpired during the interviews that were not part of our verbal discourse, and yet appeared to be ways parents displayed their love and caring for their adult children with Down syndrome. For example, after two of my interviews were completed, parents were anxious to share with me a number of their child's belongings that they treasured. Parents proudly shared with me pieces of writing and art accomplished by their children, pool cues they used, video collections, coffee cups, posters, pictures, music collections, desks, slippers, and trophies. As I reflected on this sharing, I interpreted it as a way of saying how special these children were to their parents and how much joy these parents took in being part of their children's lives. As well, in my reflective notes I noticed the number of times I had commented on parents' emotions being shared during the interviews in the forms of laughter and tears. This emotional sharing was not in the foreground when transcribing strictly verbal data from the interviews.

With consent of the participants, all interviews were audio taped and transcribed verbatim after the interview. Participants were told that if they were quoted in the study that they would be quoted as close to verbatim as possible. Parents' language would only be "tidied up" if there were repetitions, digressions, pauses, "hmmms" and the like, where it might be difficult to grasp when presented in a written form. At all times their anonymity was respected by assigning codes to each participant so that their statements could not be identified. As well, all children in this study were referred to as male to further enhance the anonymity of the parents even though one adult child with Down syndrome was a female. In the actual quotes used in writing up this thesis the adult children with Down syndrome were referred to either as "my son" or with a "______" if the words "my son" did not fit into the context of the quote.

Data Analysis

- Data were examined as a whole during the analysis of the interviews. I began by reading through all the interviews to develop a vague, intuitive understanding of the texts as a whole. I read all the transcripts together. Not one transcript was read until all of the initial interviews were completed and then transcribed. Then I went back to different parts and specific expressions of each interview and tried to develop meanings. Out of these interpretations the parts were again related to the whole. The whole interviews and different parts of interviews were read through one after another several times.
- Once I had read all the transcripts, categories/meanings were summarized in each transcript/unit; a synopsis of each interview's set of categories was typed up with a number of different categories identified in each separate interview.
- Once I had categories for every interview, I went through and identified reoccurring categories in each interview. I then returned and went through all the interviews looking for how those categories fit into themes, comparing, looking for patterns and groupings of meanings. Themes were developed encompassing all of the interviews and reviewing all the categories I had identified in each interview. I used what van Manen (1997) calls the selective or highlighting approach. The text was read several times and then I asked," What statements, phrases, seem particularly essential or revealing about the phenomenon or experience being described?"(p.93) This statement was then highlighted. Eventually my categories started to make more

sensible patterns; themes started to appear and as I progressed the themes moved into a more synchronous whole.

- The second interview was used to clarify and validate my data analysis. The parents were asked to listen to the themes I had come up with and the parts of conversations from their first interview that I thought fit into the themes I had chosen. The participants were engaged as co-analysts by discussing, clarifying, noting any distortions or exaggerations, accepting or refuting my preliminary thematic analysis. I then made corrections when necessary. The participants were never involved in the analyzing of actual text. Guba and Lincoln (1989) state that this is one method for achieving credibility, by checking with those interviewed to confirm the researcher's construction of their multiple realities. The second interview was used for further conversation, consultation, and validation of the first interview. Taylor and Bogdan (1984) state that for a study to be valid there needs to be a close fit between the data and what people actually say. It was important to be clear in the second interview that what I had come up with as themes for parent appreciation, is what parents involved in this study actually appreciated.
- To ensure soundness of the data throughout the research process I kept the lines of communication open between interviews. When necessary, I contacted the participants, in person or over the phone, to stay clear about and validate what I was doing. I then brought my results before my thesis committee for review. Changes and adjustments were made according to the feedback received.
- The final research report was developed.

Trustworthiness: Credibility, Dependability and Confirmability

Guba and Lincoln (1989) have identified major criteria for judging the trustworthiness of findings that emerge when researchers use naturalistic forms of inquiry. Although naturalistic inquiry is very different from rationalistic inquiry, Guba and Lincoln have come up with analogous terms that supplant the rationalistic terms of internal validity, reliability and objectivity (p. 246).

Credibility replaces internal validity and stands for whether the participants found my analysis, formulation and interpretations credible. Credibility was established in this study by using the participants as co-analysts.

Dependability replaces reliability and this was accomplished in one way as I kept an audit trail which outlined all the methodological steps and decision points in the research study. As well, I was open to my thesis committee accessing any of the data including memos, notes and any documentary material used in the research. Since the research committee was acting in an advisory capacity, they were allowed to view the documentation if they chose to do so. No one else was permitted access to the raw research data.

Confirmability replaces objectivity and as the researcher I continually tested to see if the study remained credible by consulting with my advisors to keep me honest, by cross checking data and by participant checks. The field notes, a reflective journal, a list of assumptions about the research context, and participants as co-analysts helped me keep this research confirmable.

Ethical Considerations

Interviewing proceeded only upon receipt of ethics approval, which was granted in December 1998 from the Faculty of Research and Graduate Studies, University of Northern British Columbia Ethics Committee.

All of the participants agreed to participate in the study. Each participant was assured of confidentiality and that all audiotapes and coding information was secured when not in use. I indicated to each participant that once the thesis was completed and defended that all the raw data would be destroyed and a final copy of the thesis would be made available to them.

The following chapter presents the voices of parents appreciating their adult children with Down syndrome that emerged from our conversations together in this research inquiry.

Chapter 4

Discussion

Presentation of the Experience

This investigation began with my wish to engage parents in appreciative conversations to provide other meanings to what it might be like to parent a child with Down syndrome from birth to adulthood. To date, voices of parents have seldom been heard in the academic and professional literature, and yet parents are the people who really understand what is involved. Voices of these parents will now be presented. By choosing an appreciative lens, asking questions, engaging in conversations and then analyzing the transcribed conversations, I acknowledge that I am a part of these constructions of appreciation I now present. This study was not a case of discovering appreciation, but rather by engaging parents in conversations about appreciation, the participants and I actively constructed these meanings of appreciation together.

Although appreciation was our focus for this study, parents did talk about their struggles and worries raising this child. It is not my intention with this study to deny these issues and I will address some of the parents' main struggles in a section on caregiving. It is ludicrous to think that parents would only share appreciation for their experiences, because parenting, regardless of the child, is fraught with challenges. Sharing some of their major concerns in raising a child with Down syndrome creates a fuller picture and provides options for further studies with parents.

Themes

The process of developing the themes began by my reading the transcripts of the conversations over and over and pulling out categories that I eventually turned into themes. In the end, I came up with three themes that I thought shared what these parents most appreciated about sharing their lives with a child with Down syndrome from birth to adulthood. The first theme did not address specific experiences parents appreciated. Instead it looked at what I saw as consistent responses from these parents upon becoming aware they had given birth to a child with Down syndrome. Once each parent became aware his/her child had been labeled with Down syndrome, they appeared to go through a process, a reconstructing of meanings in order to accept this child. Each parent went through this acceptance process each in his/her way and in some way said "yes" to this child. The second theme looked at experiences parents appreciated regarding their child with Down syndrome as a teacher. Parents repeatedly shared how their children taught them so much about themselves, life and the world. The final theme looked at caregiving and what experiences parents appreciated about that role involved in raising their child with Down syndrome.

Awareness and Acceptance – A Reconstruction Process

As I repeatedly reviewed the transcripts, I began to see a number of consistent responses from parents that occurred after the birth of their child with Down syndrome. These responses appeared to involve a letting go of the "perfect" or "normal" child concepts and reconstructing new meanings around this child and parenting this child.

In the literature review and the transcripts, parents repeatedly talked about the ideas of the perfect child or the normal child. Barbara Levitz, whose son is an author and also has Down syndrome states, "Absolutely nothing prepares you for being told your newborn child is less than perfect"(Kingsley and Levitz, 1994, p.1). Marilyn Trainer (1991), author of *Differences in Common*, and mother of a child with Down syndrome states, "When I first learned that our baby, that rosy, dimpled infant, was retarded I almost died of agony. The doctors were wrong…our Ben couldn't be what they said, a child with Down syndrome"(p.37).

With the concepts of the perfect or normal child gone, parents in this study appeared to begin their own forms of reconstruction to somehow fit this child with Down syndrome into their worlds. In this reconstruction process I saw consistent responses from parents as they reworked the idea of parenting, somehow coming to accept this child with Down syndrome whose label was dominantly constructed to mean so much about difficulties and burden.

A Comparison

I came across a pamphlet with Emily Kingsley's *Welcome to Holland*, a mother's short story that compares the experiences of raising a child labeled with a disability to planning a fabulous vacation trip to Italy. I want to share a short, edited version of this story because the comparison she uses works so well to illustrate the consistent responses parents in this study had to the news that their child had Down syndrome. Kingsley's comparison begins with you imagining that you are planning a fabulous vacation trip to Italy. After months of eager anticipation and preparation, the plane arrives and away you go. Several hours later the stewardess announces, "Welcome to Holland." (Awareness – this parent is told his/her child has Down syndrome.) However, you hadn't planned to go to Holland. All your life you had dreamed of going to Italy. But there's been a change in flight plan and the plane landed in Holland and there you must stay. So you must go out and buy new guide books and learn a whole new language. (Process of acceptance begins as parent starts to reconstruct ideas on parenting.) Holland is just a different place, slower paced and less flashy than Italy and after you have been there for a while you catch your breath, you look around. You begin to notice Holland has windmills, tulips, and even Rembrandts. If you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special things about Holland. (This parent now has constructed some new meanings; he/she is accepting and appreciating this child with Down syndrome for who he/she is.)

Awareness

Awareness that a child has Down syndrome appeared to come for most parents shortly after the birth of their child. (However, one mother in the study did not learn her son had Down syndrome until four months after his birth, and another mother found out several weeks later.) Parents expressed many strong feelings and stated they had a real lack of knowledge about the label Down syndrome.

Marilyn Trainer (1991) an author and mother of a child with Down syndrome writes about the powerful feelings she experienced when she and her husband became aware that their fourth child had Down syndrome. Trainer said that two feelings were very strong for her – that of unmitigated responsibility and helplessness, exactly how she felt facing raising her new child with Down syndrome. She did not want the responsibility of raising this little baby. Unprepared and on the brink of despair, she felt helpless to do anything for someone she judged more helpless than herself. She says she went through feelings of anguish, fear, guilt and shame as she faced having a child labeled with Down syndrome.

Parents in this study talked about becoming aware that their child had Down syndrome, the feelings they had and the not knowing what that meant for them or their child. At this point there was no celebrating, no appreciating, no conversations about joy. With the birth of a child with Down syndrome into a world that has dominantly constructed Down syndrome to mean abnormal, unhealthy and mentally challenged, these parents did not feel appreciative:

> It's very difficult to realize you have a handicapped child. It is a disappointment. I mean you expect so much from your offspring to be able to make a little mark for themselves in the world...and you wish you had the perfect child.
>
> ****
>
> You first start off thinking this is a burden and it's a life time burden, its not one that's at the age of 18 going to move on.
>
> ****
>
> When they broke the news that our son had Down syndrome I asked, 'Well how handicapped will he be? How retarded is he going to be?'...As with any child you expect this perfect little child who will come out and say, 'Hi, here I am world, I'm perfect, and I'm going to take it on.' And with our son, I lost it.

****

> I was terrified and I was ignorant as all get out. I was lost about handicaps. I'd never actually been in contact with anyone with any kind of handicap.

****

> I never, never heard of a mentally retarded person until (our son) was born. I didn't know what it meant.

****

> I couldn't believe that he was born with Down syndrome. I went to the doctor, 'Well is there something you can do about this?' That's how naïve I was.

In these descriptions parents appeared to have no idea what having a child with Down syndrome might mean. They talked about disappointment, terror, still wishing for the perfect child, about wanting to do something to change the circumstances, not wanting to acknowledge that this child was different from what they had planned. The moment when parents became aware that their child had Down syndrome appeared to be a time of immense confusion and feelings, a time of questioning, a time of letting go and loss. Parents at this point appeared to have to begin to negotiate new meanings that worked for them in this situation. Their given accounts of the world around parenting and having the normal child or the perfect child were no longer viable, therefore not sustainable. According to constructionist theory, meanings are continually negotiable until we find something that works for us. Now that they had a child with Down syndrome, parents in this study appeared to go through a process of reconstructing, of accepting, finding different meanings that worked.

Acceptance

From the parents of this study it seems acceptance means to go with life, and make peace with or content oneself with one's situation, to say "yes" to and acknowledge a child that historically and culturally, has not been warmly welcomed. This definition agrees with the WorldWide Webster dictionary's broader definition which states acceptance means to receive willingly, or to give admittance or approval to. A parent described her letting go of the idea of normal, acknowledging that her child with Down syndrome was different and stating her expectations as a parent needed to be revamped (reconstructed):

> All the expectations you have for this normal child go out the window. You have to totally revamp….So the hopes and dreams you have of your son going on to do this, you don't have that any more. So you have to totally restructure your thoughts about how you are going to look at this kid, you know as a life time thing.

Another parent shared how her conceptions of parenting the perfect child had to change as she acknowledged and accepted her child with Down syndrome. This mother shared how important acceptance was to her:

> You have to take your own ideals of what you thought life was going to be, this perfect child you're going to have and you didn't and all of a sudden you've got one you've got to change your ideals on, …you have to learn to accept this….It's one of the very first rules really because if you don't accept your own child, you don't accept him for who he or she is…nothing will mean anything.

Another parent gave an example of how accepting her son as someone with Down syndrome, she could appreciate him just as he was. She talked about no longer wishing for her son with Down syndrome to be normal because being a person with Down syndrome is part of who he is. Being normal is no longer part of the terms or forms that are important to her in relationship to him. She has negotiated new meanings:

> If somebody could come and make him, as they say normal, or not Down syndrome any more I wouldn't want it because I think my son is very happy with his life and I'm certainly happy with him and if he wasn't Down syndrome, it wouldn't be him. Like it would just, it just, it wouldn't be him anymore. It would be somebody totally different and that's not what I want. I love him because of who he is and I don't want to change that.

A mother shared a new and different meaning of the word perfect. In this new meaning or reconstructing of the concept perfect she states how she no longer saw imperfection but saw Down syndrome as a part of him and a part of her new version of perfect. She no longer wanted to change him and now accepted him as he was:

> They will bring joy to your life and that's really hard to see when you have this imperfect child. It's not that he's not perfect because he is perfect. But he is perfect because he is ____, he's perfect because he has Down's and that's what he is perfect in. I wouldn't change it, I wouldn't change having ____, as I said it would be a void without him....Because I've learned to accept him, I've learned to accept me...as much as I never would have said this when he was born, I wouldn't change having him.

Other parents talked about acceptance and appreciation for this child in their lives. Acceptance came up over and over again. Acceptance appeared to be part of reworking the meanings of parenting and having children and then appreciating these new constructions:

> I think that's the end result, if you can see that joy of where your child is, to accept him or her, you know, as their own individual person and to accept their limitations and to revel in the growth that they see in their life.

Acceptance - Uniqueness of the Process

In the many conversations that I shared with parents the concepts of acceptance were similar and yet parents' experiences were unique. Two participants described having experiences where they could remember consciously shifting from denial and wishing for a normal child to accepting their child with Down syndrome, they described it was a precise moment in time when they made a conscious decision to accept this child.

One mother said that she did not find out that her baby had Down syndrome until her baby was four months old. She said that this was her first baby and that she was quite young and inexperienced and therefore treated this baby with Down syndrome as if he was normal. When she found out that he had Down syndrome, for her, he was already a little person with a personality all his own, her child, and he had no other label. When she was told he had Down syndrome she remembered feeling upset and that she didn't know what to do. Then about ten days later she woke up one night and very clearly remembers a "moment of revelation", where she asked herself the question, "Why am I feeling so sorry for myself?" At this point she said she made a conscious choice to focus on her child and accept whatever was to come. In this moment of revelation this mother appeared to accept her child with Down syndrome.

A second mother told her story as she remembered it. She said that she was home alone sitting in the living room with her six-month-old baby close by sleeping in his crib. She remembers the sun was shining brightly into the room and her mind was full of all the terrible prognoses the doctors had given her about her son. She explained how she had cried for months and that she had only one wish and that wish was for her child to be normal. Suddenly she said this indescribable feeling came over her. She described it as a moment of "resignation and peace", a letting go, and an acceptance. She decided at that moment that she would accept her son. These two mothers were the only two that talked about a specific moment in time where they consciously chose to acknowledge this child as a child with Down syndrome, a child not considered normal, and accept him and all the experiences that life would bring as a result.

Other parents talked about the amount of time it took them to accept their child. The time frames they described ranged from almost immediately after birth to what one parent described as "a long time". One couple described their process of acceptance as almost immediate:

> A day after the birth I went to my wife, she said I know about this and he's ours and we just have to do our best. Well right then my strength changed a lot…she was the rock but it didn't take much time at all to realize that this was my child.

This father talked about how quickly both he and his wife acknowledged that this baby was their child and they would do their best. The circumstances this couple faced were different than other participants in that right from the time their son was born with Down syndrome, his survival was severely threatened because of congenital defects. They shared how these circumstances put a whole different perspective on things and how acceptance was expeditious for them because they were so involved in their son's struggle to survive. To this day they say they have maintained an "accept it versus fix it" philosophy.

Another set of parents talked about how the idea of acknowledging their son was different and accepting him came fairly easily to them because once they became aware he had Down syndrome they "just got on with it":

> Father: He's obviously different from the normal child…but it has never bothered me and I don't believe it ever bothered my wife.
>
> Mother: First accept….He was our child and he was going to be brought up.

For other parents, their process of acceptance seemed to transpire more slowly. Trainer (1991) suggests that when parents first find out that their child has Down syndrome they may develop another kind of syndrome whereby they repeat over and over again, "Why us? Why us? Why us?" (p.3) One mother in the study talked about this type of experience where she compared her process of acceptance to a grieving process. This process involved the letting go of the idea that her child was going to be born and be a certain way in the world, a reconstructing or negotiating of new meanings. She described this process:

> The first two months, I don't remember but they go in a blur because you're still accepting this, the 'Why me God' type of idea. And it takes a long time to get

> over that, a long time. It's like having a death, and you go through the grieving and the recovery, the same thing....but the first six months is tough, it's very tough.

Another mother described her process of acceptance as " a gradual process". An example she gave of this process was how she did not tell her other children for the first three years after having her baby with Down syndrome, as she wanted them to treat him as normal. When she finally told them they were surprised. However, she said that her son with Down syndrome was already an accepted part of the family for who he was as a person and so there were few reactions to the label Down syndrome.

In my conversations with parents, it was apparent that appreciating their child was not something that just happened. When parents first became aware of their child having Down syndrome there were many feelings, many wishful thoughts that their child could somehow be normal or perfect once again. However, upon realizing that there was no trading their child in for a normal version, the renegotiating of meanings began around that child and themselves as parents and accepting this child. This was not a clear-cut process as real life experiences are often blurred and intertwined. However, similar and consistent patterns of responding appeared to emerge and each parent in this study, in their own unique way said "yes" and eventually accepted his/her child with Down syndrome, they no longer wanted to change him, or trade him in for normal.

This acceptance process, this reconstructing process, is part of our constructions of appreciation in this study. Consistently the parents in this study let go of the concept of the perfect or normal child and said "yes" to this child and accepted this child, who within dominant constructions is considered abnormal and disabled. One parent sums up this process of reconstructing, of accepting, when she states:

> And now I sort of go well, my son will fit where he fits. I learned to readapt and refocus and rechange and just look at how he has grown and where he's now fitting into society.

Child as Teacher

The second and third themes in this study look at experiences parents talked about appreciating having shared their lives with this child with Down syndrome from their birth through to adulthood. Repeatedly, in interview after interview, parents talked about appreciating what their children with Down syndrome had taught them about life, about themselves, and about the world. Parents talked about how much they had learned. Parents' dreams and expectations shifted as their children grew and became an integral part of their lives. Acknowledging and accepting their child with Down syndrome and watching this child grow and develop was a learning experience for all the participants in this study. Having a child with Down syndrome somehow seemed to enlighten, illuminate, or teach things that these parents might not have experienced if their child did not have Down syndrome. This theme of "child as teacher" is not aimed at sentimentalizing or as Marilyn Trainer (1991) would say "adorning (them) with a mantle of the supernatural"(p.64). People with Down syndrome are not "mongoloid idiots" and neither are they "angels". However, to these parents their children with Down syndrome were and still are teachers. These parents appreciate what these children have taught them or are in the process of teaching them.

Learning on a Deeper Level

Every child, every person, is a teacher in his/her own way. As human beings we learn and construct our meanings together in contact with each other. Parents in this study talked about how much they appreciated learning things that they might not have learned had their child been born normal. Somehow, this child with Down syndrome taught them in ways they had not expected. A mother compared her experience of parenting her child with Down syndrome to the experience of parenting her other children and shares how every child has taught her something but her son with Down syndrome has taught her more at a "deeper level":

> He's taught me lots. I've taught him lots but he's also taught me more... You will learn something from his downfalls, you will learn from his joys, you will learn from everything but at a greater scale than you would from a normal child.... You learn all the way through his life and I'll continue to learn....I think every child teaches you something and he has just taught me more on a deeper level than my other kids have.

One might wonder what this mother meant by "more on a deeper level" and she goes on to share what "deeper" meant for her:

> He's taught me, I think humility. I mean he's taught me all the basics that we tend not to learn....He's taught me patience and he's taught me just acceptance of people ....You learn to be humble about things because you learn to take the stares and you learn to take the questions that other people have of you....He's really taught me that, patience....I've learned to be more patient with him because

> I have to be.... he's taught me to look at life differently, very, very differently. You see things you wouldn't see before. (Mother starts to cry here).

This mother suggested that she has learned at a deeper level with this child and she sees things she never saw before. She approaches life differently because of what she has experienced with her child with Down syndrome. The differences in the way he looks, how he learns, and how he interacts with others, this mother suggests, have all been opportunities for her to learn about humility, patience, and acceptance of others. It appeared that she felt very strongly about what she was saying. Her words, her tears, the tone of her voice, her having to stop and to take several deep breaths suggested that this mother had strong feelings of appreciation for the experiences her son had brought into her life. The lessons he taught her at a deep level were valuable to her in her life now and her constructions of the world were different as a result of having this child with Down syndrome in her life.

Acceptance of Others

Many parents talked about how they watched their children with Down syndrome openly accept others without judgement. Parents commented on how their children with Down syndrome did not seem to use the same criteria for judging others as many of the normal population might:

> You know we cannot just accept people. My son doesn't have that. He does accept everybody. Like it's so different for him, to look at a person and he just accepts them for who they are and the general population doesn't do that. He does. So he's taught me that.

A "rewarding experience" was shared by a couple as they witnessed their son's ready acceptance of a woman whose face had been seriously scarred and disfigured from burns. His reaction was quite different from their initial reactions. They noticed and appreciated his acceptance:

> Mother: One thing that was really rewarding for me... for all of us was when...the lady who worked with them had been severely burned in a really bad fire....Then this opportunity came up to work with (our son)...and that was the first time she actually had come out in the public eye.... she was incredible with him and at the same time it helped her...I can remember the first time I looked at her. It was all I could do to look at her face, it was just
>
> Father: It was hard. She was really badly burned.
>
> Mother: And then the more you got to know her you didn't see the physical anymore. It was the total personality.
>
> Father: I'm convinced that our son in the beginning didn't see the physical.
>
> Mother: No he didn't.
>
> Father: ...to our son she was just another person...he has been always a very compassionate, loving person....He has a warmth about him that is rather special, I think...he treated her like anyone else. There wasn't the staring, there wasn't the questions.
>
> Mother: No he never stared at her. He never really asked her questions because (Mary) was (Mary) and (Mary) was fun...And that was all (our son) saw.

This ready acceptance of others, regardless of differences seemed to be a lesson these parents appreciated. On a holiday, one mother noticed how her son responded to a difference in colour: "He said, 'These people are black.' He noticed the difference and yet he's very accepting. It didn't make any difference to him. He didn't care about that." Or another mother who was aware how her son responded to people asking for help on the street:

> We often say so and so and such and such and judge them before we even know. So I think he has a lot of compassion for people. And even for going downtown. If he sees somebody there with a hat or a hand out or whatever, he always reaches into his wallet and gives him or her something.

Experiencing life with a child with Down syndrome appeared to give parents and siblings many opportunities to learn about becoming more accepting of other people's differences themselves because of the differences in their child:

> I never had an understanding. I remember as a child though…I teased people that were handicapped when you're in groups where you stared or whatever, so he's been good for me in that respect.

A father shared:

> It's been rather enlightening and it gave me a greater appreciation for those people that are this way. You know I expect I always kind of would look over my shoulder if I saw someone go by like that. But now, heck, they all call me by my first name….I feel that's an achievement that I've been able to experience whereas I wouldn't of, if I hadn't had a Down syndrome child.

In conversation, one mother talked about her life and how she appreciated her shift from what she considered selfishness and pride, to one of more humility as she experienced life with her son. Through her experiences with her son, she learned to be more accepting of others and their differences:

> I don't think I'd be the person I am today. I think I'd be more selfish and I certainly am more humble. Before our son was born I was quite proud of myself, thinking that a lot of things I did were superior to other people...and he just let me see that...everybody is the same and nobody is superior to anybody else and then I saw people in a different way, I could see sort of where they came from, I wasn't so judgmental about them...what they could and couldn't do, or how they dressed or how they didn't dress or how they looked or how they talked.

Parents noticed that their other children's acceptance level of others' differences shifted because of the presence of a sibling with Down syndrome. This mother shared how she appreciated that her other children had had an opportunity to learn:

> He benefited my own kids in the way that they have a better understanding. They have more compassion towards any sort of handicapped person or anyone....I've never had to say much because he was just part of the family and was treated very equal....There was never any embarrassment....They all feel like me, we're so lucky to have him.

Somehow having a child with Down syndrome appeared to affect how parents and sometimes how whole families experienced themselves in the world. In my conversations with parents they talked about how much they appreciated these shifts.

As parents experienced life with their child in a world full of judgements, they suggested that they found themselves and at times their other children, becoming less judgmental about others and more accepting of differences because of their experiences with their child with Down syndrome.

Acceptance of Self

Acceptance of others was not the only type of acceptance that parents talked about appreciating. One mother described her son and gave a picture of his self-acceptance:

> He is proud of who he is. He doesn't want to be like other people, whether others consider him too short or too fat or whatever he is, he doesn't even think about being different, or to be like other people are or look like them…our society today is too self conscious of how they look or who they want to be like instead of being proud of being who they are. And so I think that's a good lesson to learn from my son….He is never trying to be anybody else or look like anybody else. He likes to look neat and tidy but he is always proud of who he is….He is never afraid to dance by himself or sing as loud as he can. A lot of people are afraid to do these things....And he doesn't think what anybody else is thinking around him or looking at him…but he loves to do those things and he does them. And I think we have to learn a lesson from that. That we shouldn't always think what other people do or think of us when we do things but do them if we feel it in our hearts that that's the right thing to do and that's what we want to do, we should do it.

Wong and McKeen (1998) state that "it is rare to encounter people who appear to have achieved such a comfortable state of being. More commonly, people seem to suffer from low self-esteem" (p.50). As I read over this mother's description of her son's acceptance, she appeared to have encountered something about her son that was "rare". He did not worry about others judgements he just seemed to like being himself. Another parent said she learned to accept herself through her child with Down syndrome, "My son taught me how to accept myself...he's taught me how to be accepting of me and how I look at things and of just who I am."

Distinguishing Characteristics

Parents shared how they appreciated their children with Down syndrome as they learned from them as they watched their children experience the world. There were different characteristics that parents respected in their children with Down syndrome. Each child had different ways of teaching and yet parents talked about learning and seeing things they might not have seen had their child not had Down syndrome. Parents talked about learning about forgiveness, new dimensions to loving, taking time to stop and smell the roses, determination and pride in accomplishments, and improving family dynamics. These characteristics that they saw in their children taught them something about life and about the way they viewed the world.

Forgiving and Loving

Some parents appreciated the forgiving natures of their children; "He is always ready to say I'm sorry. And I think that teaches us a lesson in forgiveness"; "He doesn't hold grudges or resentments. He's very, very forgiving." All of the parents talked about their children's loving nature, "He brings us an awful lot of love. He is full of love"; "He just loves the family and family occasions. Our son responds to love, doesn't he....He also gives an awful lot of love"; "My son in himself has such a loving disposition....He's very easy. He was so easy going, like anything went...he just enjoyed doing everything, just so easy"; "Our son doesn't have one mean bone in his body....He doesn't look at the bad things in people"; " He looks on the bright side of everything. He's such an optimist. He loves everything." One mother shared her thoughts on the loving their son had brought to their lives:

> We didn't know what love was until he came into our lives. My husband once said it's a whole new dimension. And I think it's because you really discover what love is.

Stopping to Smell the Roses

A common complaint today in our society is that people's lives seem so busy that often the everyday things go unnoticed. There is a phrase coined in our society that describes a busy lifestyle, people not taking time to "stop and smell the roses". The following conversation tells one mother's story of the appreciation her son with Down syndrome has for those things considered ordinary by many people in our society and what it has taught this parent watching his appreciation of things others may often think of as mundane or inconsequential:

> He shows us how great the gift of life is and that each day should be lived to the fullest...just by the little things he appreciates. You know it doesn't matter whether it's a cup of coffee or going out with friends or all the kinds of

> celebrations we have like birthdays and anniversaries.... He seems to enjoy the things that are in that moment. And another thing too, I think he shows love for things....I think a lot of things, as I say you take for granted. I mean your house, your job, other people, your family...but I think we forget those small things....We should be thankful for them and I think that is what he is telling me anyway. That we should be more aware of the things that we have especially for family and friends.

Marilyn Trainer (1991) agrees with this mother as she watched her son experience the world. She considers her son with Down syndrome fortunate:

> He is lucky this little boy of mine. He will not conquer the worlds of the academic, the scientific, or the great doers. But he has a unique appreciation for those ordinary rites of life that seem only dull and jaded to the rest of us. (p. 38)

In watching and relating with their children with Down syndrome, parents appeared to be aware that they wanted to take time, to stop, to appreciate the moment.

Determination and Pride in Accomplishments

In this busy, industrialized, highly technical world people will often look at how individuals with Down syndrome might take longer learning something or struggle more in attaining a certain skill and judge this to be negative. Yet several parents that were interviewed looked on these struggles and the determination with which they were met as something they appreciated and learned from. One father shared:

> I think the thing that stands out in my mind was the way he conquers things. The way he is able to put his mind to something and do it. And he does it and he

> proves to himself and to us that he can do things on his own without any help from anybody else.

A mother shared how so much is taken-for-granted, even in how easy it may be to learn something. Examples she gave were of things like tying shoes, eating with a knife and fork, swimming, skating, and learning how to deal with money and tell time:

> It always takes our son a lot longer to do, learn things….All those sort of things we take for granted it took him longer. But he did them because he wanted to do them and he must have known he could do them. And I think that helped us too in our daily lives in some of the things you sort of want to give up on…you think oh I can't do that, just let it go….I think that is one of his big attributes is his determination to do things and he does them.

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> He's made us appreciate the fact that he is handicapped and what he has been able to achieve.

Another mother talked about learning to appreciate and enjoy her son's accomplishments even though she suggested the milestones in his life were smaller. Regardless of the size of his accomplishments she says she is learning to appreciate each step as he is teaching her something as she watches his process:

> So it's different. You take each day at a time. You know you look at the small steps that they make and you enjoy and have joy in those steps because they are smaller. Each little milestone in his life will be smaller, but it's smaller in the overall picture, but it's a great step for him. And you have to learn to enjoy those

> steps and just love him….As much as you are there to teach him; he's there to teach you as well.

Family Dynamics

Parents talked about the influence that having had their child with Down syndrome had had on their personal lives and what learning they had had in the experience as they related to one another and as a family and the gratitude and appreciation they felt for the experience. Although the experiences were sometimes really tough, this father suggests that these difficult times brought them together and broadened their lives a lot:

> Mother: And I think to have survived as a couple and as a family in the face of adversity and in the face of having to work at something
>
> Father: It's a good point. It's brought us together.
>
> Mother: It didn't rip us or tear us apart.
>
> Father: But it's sure made us a hell of a lot stronger…he has brought us together. Sure it's made us go through tougher times but as a result of those tougher times it's broadened us a lot.

This couple stated that their son with Down syndrome brought their family together and they imagined that they wouldn't be as close a family without him:

> I think we've been closer because of (our son)….It's just all the family, you know like they want to do things for (him). And they just all love him….You know at our age most of them would be into something entirely different but they want to stay close.

A teacher is someone people often equate with schools, degrees, and some sort of recognition by society. However, one parent challenges the idea that you need a certain level of intelligence to be a good teacher:

> He is a blessing. If there was any blessing, he is the greatest blessing. I think some of these people teach us a lot more than any teacher has ever taught.

Looking back on their experiences, parents appreciated all that they had learned. Each parent had had different experiences, yet frequently many of the responses they shared were similar. These parents' stories came across as genuine, raw and powerful. Listening to their stories captured some deep, important challenges to some of the more dominant discourses about people with Down syndrome. Elkins and Brown (1995) state that individuals with Down syndrome teach the rest of us how to cope, to grow, to overcome, and to understand humility, gratitude, and joy. By looking at parenting a child with Down syndrome from birth to adulthood through an appreciative lens, parents in this study shared how much they had learned from these wise "teachers".

Caregiver Appreciation

Parents of a child with Down syndrome are faced with issues and challenges that are different from most other parents because they are raising children who often have intellectual delays or physical challenges. For the purpose of this study, I define this different role by using the term "caregiver" or the act of "caregiving" which are common terms used with people who are responsible for others' care. Heller (1993) states that "most families of persons with developmental disabilities provide life long family based care for them"(p.22). The term "caregiver" that I use in this study, is based on this idea of family-based care through a lifetime. The term fit for this study, as participating parents are still responsible for their adult children with Down syndrome. Their parental responsibilities continue despite the fact that some of their adult children with Down syndrome were living away from home in "out of home placements". Their care is different in these cases of out of home placements and not so physically involved, however, these parents are still actively involved in their children's care and in choices about their care.

Caregiving to the parents in this study had a variety of meanings and they described what appeared to be multiple, complex layers to their roles as caregivers for their children from birth into adulthood. Talking to parents, it was evident that there were many experiences that parents appreciated about the role of caregiver through their children's lives. This became my third theme.

For some parents caregiving was a total immersion in the care of their child. For these caregivers, caring had become the center of their lives at some point, and they derived great pleasure and meaning from their caregiving role, they appreciated all the satisfaction they took from caregiving. There were other parents who appreciated their caregiver roles, and yet caregiving did not appear to be so all encompassing. Part of the caregiving role for most parents was becoming advocates for their children from birth, through school age and into adulthood. In this role as advocate, parents were involved in efforts to further their children's achievements and set goals. Some parents noticed that as their children got older, their advocate roles changed. Not only were they advocates in their adult lives for employment opportunities, training, etc., but they became educating advocates, sharing their knowledge and appreciation for their child with Down syndrome with other parents of children with Down syndrome. Along with this role of caregiver as advocate, came the rewards, the appreciation that parents felt when they realized that their advocating, their hard work, had helped their child with Down syndrome achieve things they never thought possible. Parents really appreciated being able to see their children be successful in this world.

Before I go on to describe appreciation about caregiving, I want to address the struggles of caregiving because struggles did come up in conversations despite our focus on constructing appreciation. There are many challenges parents face as long-term, lifelong caregivers. To deny these difficulties would be similar to denying that there are things parents appreciate about caregiving.

Caregiver Struggles

As we shared conversations, parents discussed some of the problems they faced parenting a child with Down syndrome. There were many obstacles, challenges, fears and disappointments as well as joys, rewards, and appreciations. One of the difficulties that one couple talked about was their child's struggles with speech and motor coordination and how difficult it was for them not to be able to do anything:

> I know its hard, but you have to sit back sometimes and swallow and say, 'Well you know so you know he might not be able to do this or he might not be able to do that but he is going to be able to do this'....We had a person who was amiable and wonderful who you could take anywhere but who had a lot of speech problems, who was difficult to understand and we had a hard time communicating

> and a hard time with motor coordination…my son has limited ability…those are sort of the negative things but they're the facts.

For some parents there appeared to still be a longing for what they considered to be the normal child. There was a sense that their child was really missing something by not being normal, not being able to do what they considered other people his age were capable of doing. These phrases from two different parents describe this concept, "This guy loves his sports so much, he could excel if he was normal"; and:

> This is where I feel very badly for my son, he will not have a family of his own….I can say that I do envy people who have normal children his age because they have much more future than my son ever will.

Another conflict for one couple was when their child moved out. They were ready and yet it was still difficult:

> When reality (their son moving) came it was a bit of a shock…and I think to us the biggest adjustment…and I just think both of us thought…you're not staying home until you're 42 years old….I think for a lot of people it is really hard to let go.

One of the biggest worries for older caregivers was what would happen to their child with Down syndrome upon their deaths. Even when their child was no longer living in their home they worried about who would care for him as well as they would after they were gone; "I have one fear…I hope in some ways my son goes before I do because I don't want to go not knowing that he is looked after"; "What's bothering my wife and I right now, really, is the fact that what's going to happen to him when we are gone."

However, one mother shared how struggles, heartaches, and difficulties for her were mixed with appreciation and joys. She appeared clear that for her the joys have outweighed her burden:

> I think of all the things that I do tell new parents when they have a child, is that they will bring special joy…I mean there is a lot of hard work, a lot of heartache, a lot of you know, mental abuse that goes along with it in your life. But there will be joy, and the joy will far outweigh all the rest. That there will be benefits and that's the parenting.

Appreciating the Caregiving Role as a Purpose in Life and for Companionship

The parents in this study for whom caregiving appeared all encompassing or the center of their lives suggested how caregiving made their lives worthwhile. In some cases, the presence of an adult child with Down syndrome in the home provided parents with a clear purpose to keep going, to continue on, "my son set my life free… I mean I couldn't bear it, separate me from my son and you'd destroy me"; "It gives me a reason to get up in the morning"; "You have a purpose if you have a child with Down syndrome"; "I did a lot with my son and I found it fascinating…I didn't have a job so this became my purpose or my focus… this became an enchantment for me…that I had a focus I felt worthwhile"; and "You just can't sit down and die because we've got our son to keep us moving, keep us busy." These phrases suggest just how important these children with Down syndrome are in the lives of some parents and how much these parents appreciate how everything changed when her son got married and a third person came into the picture. Her son was no longer her primary companion because now he had a wife:

> A little selfish part of me is we have so much fun traveling together…and I kind of thought …we're gonna to travel the rest of our lives and I'll take him and we'll have fun and….I was quite happy about that and then all of a sudden I lost my travelling partner...you have this long term range and I thought he would sort of be with me forever. Like when the other kids grew up and were gone, it would be my son and I. I never envisioned a third person.

Caregivers as Advocates

Not all parents saw their child with Down syndrome as their "life's purpose" or as a companion into old age. As caregivers, parents saw their roles differently when it came to how much emphasis they put on caregiving as part of their lives and where their child fit into their lives as they got older. Some parents desired complete independent living situations for their adult children and had planned for independence from an early age. One parent said, "It was always determined that our son would eventually not be living at home…I think he enjoys the joys of independence"; another said, "He needs to be on his own."

Regardless of the different amounts of emphasis parents put on their caregiving as part of their lives, or how much companionship they wanted in their lives as they got older, one purpose that appeared to be common to all the parents in their roles as caregivers was that they became advocates for their children in one way or another throughout their children's lives. One parent put it very clearly, "You have to be an advocate." As parents described the advocating they did and still do for their child with Down syndrome, words like supporting, defending, and promoting came to mind. Some parents associated their advocating for their children as part of the reason their children were able to accomplish things they never thought possible. These parents appeared to appreciate their advocating because of the part they felt this played in their children's successes and accomplishments. One parent was able to describe the difference for her between advocating for her child with Down syndrome and advocating for her other children. I get a sense that advocating in her caregiving role is different because of the amount of time and intensity involved:

> You become an advocate for your child and I mean you always are regardless, but you're far more so with a special needs child…you have to be an advocate…with school, you just basically have to really look out for him….your role changes type idea…you really have to go after what you want and what you think is good for your child because if you don't he won't get it….don't be afraid to step in and stand up for him.

The school system appeared to be a place that many parents became strong advocates for their children with Down syndrome. A husband talked about his wife and her role as an advocate for their son within the school system, "She's worked harder than anybody I know who's had Down syndrome children from the standpoint of studies, working hard to change the programs within the school system." Other parents talked about how having a child with Down syndrome has created experiences where they had chosen to advocate for these children, something they might not have done if their children had not had Down syndrome, "I know as far as the education system goes, it made me get off my duff and confront things I didn't like"; and:

> I had to fight through the school system for a lot of things and that fight just sort of continued on and on and on. You always had to be his advocate and be up there, you know, I want this and I want that.

Advocating for their children seemed to be something where parents immersed themselves when their children with Down syndrome went to school.

However, advocating for their children did not stop when their children finished school. It was something described as continuing "on and on and on." A mother shared how as her son has gotten older, she is now, "another advocate for him in where he'll go and what type of job he'll have…still looking out for him, directing him." Another mother talked about how the ways in which she advocated for her child changed as her child got older and graduated from high school. She now is advocating with, and educating other new parents by sharing her experiences as a parent of an adult with Down syndrome:

> The role changed and you became an educator…you go out of your way to make a comment and comfort people, to educate them just about what Down syndrome is about and how well these kids do…all of a sudden you're an educator which is not a role that I would normally think of myself...you're going to give them your advice…because I appreciated when our son was little…it's nice to relay sort of positive things and the special joys.

Now that her child was an adult, this mother wanted to do the same for other new parents that more experienced parents had done for her when she was a new parent. She wanted to focus on the joys and the positives as a way of comforting and letting them know that there are joys to parenting a child with Down syndrome and she appreciated being able to do this for other parents.

Children's Successes

Interviewing parents for this study with adult children with Down syndrome, many of these parents had faced difficult and very negative prognoses from health professionals upon the birth of their children with Down syndrome. In the past, even the best trained medical practitioners informed parents that their children with Down syndrome would never be able to walk, talk, dress themselves, have a single meaningful thought or even recognize their parents (Berube, 1996; Hunt, 1967; Kingsley & Levitz 1994; Williams, 1995). This was the case for many parents in this study. Some parents were encouraged to institutionalize their children, "The doctor wanted us to leave him there (hospital). And I couldn't, I couldn't leave him there"; "He was an idiot and should be put away and forgotten"; "It's your child and there is no way you're going to put him away"; "There was no way that we were, I was going to let them put (our son) in anywhere. No way." One mother gave a clear example of how the process of advocating for her son began right from the time he was born:

> My doctor wanted me to put him in an institution right away and that was the last straw…that enraged me and I became very rebellious and I said well if it takes

> the last breath in my body he'll get as far, he'll be accepted in society, and we'll bring him along as far as we can.

After advocating for their child since birth and battling the prognoses of the doctors, watching their children succeed and accomplish things they would never have imagined was something parents gained a great deal of satisfaction from. One mother shared how she had been an advocate for her son and worked very hard with him and so every accomplishment for him was "a feather in her cap" as a caregiver. Watching her child accomplish a wide range of challenges, gave her great satisfaction and fulfillment as a caregiver because of the effort she had put into her caregiving role:

> I remember just how rewarding his accomplishments were….Every little accomplishment is absolutely huge, different than your other children that automatically do everything and that you work so hard towards, that he works so hard towards…going through high school and then advancing to college and doing all the things that I probably never expected him to do….I basically was told that he would probably never read and he wouldn't write and he wouldn't do all these things…everything was just exceeded, everything I thought would ever happen. And then I guess the last eventful thing was him getting married….It was just perfect and probably something that I in all expectation probably didn't expect to happen…you just keep getting the rewards year after year and you know its quite amazing.

Another parent stated to see her son "develop and grow and mature and be an active part of society is really a plus for me. That's really, that's to me is really like wow." Parents appeared to celebrate when they thought their children with Down syndrome had succeeded. One parent said that she learned to appreciate the small accomplishments, "the small steps they make and you enjoy and have joy in those steps…little milestones." One of those milestones for a father was how happy and proud he was for his son when he graduated:

> The most positive time he had, the most exciting time he had has to have been his graduation….They actually have a videotape of the grad, which lasts about two and a half-hours. He plays that constantly, backwards, forwards, he knows everyone of the four hundred kids there and it was a real highlight for him….We were very proud of him.

The caregiver role and all the different ways parents experienced it appeared to be a role that these parents appreciated as part of parenting a child with Down syndrome from birth to adulthood. For some parents this life long or long-term caregiving from birth through to adulthood and beyond appeared to create a sense of feeling needed. For some parents it provided a purpose for living, a reason to get up in the morning. For some parents it allowed for companionship. For all parents in this study caregiving involved advocating for their child and then experiencing pleasure and appreciation in seeing their children's accomplishments.

Chapter Five

Summary of the Study

Two primary premises of this study hold that the way we converse with others is a key factor in the meanings we construct and that these meanings are continually negotiable. This research was about negotiating new meanings and challenging the engrained patterns of language used in our culture to describe Down syndrome and parenting a child with Down syndrome. After reviewing the development of biomedical, historical, and cultural forms of discourse about Down syndrome and parenting a child with Down syndrome and judging them to be largely negatively skewed, I chose to have conversations with parents of adult children with Down syndrome that focused on experiences that they appreciated. I wanted to look at the assumptions that are taken-for-granted about Down syndrome and parenting a child with Down syndrome and open spaces for other ways of thinking.

Drawing on these concepts from constructionist theory, nine parent participants and I constructed the findings in this study together. Through our conversations and research analysis, validated later by the participants, I came up with three central themes regarding experiences appreciated by parents of children with Down syndrome spanning the time from birth to adulthood. The first theme looked at what I saw as the reconstructing process parents appeared to go through after they became aware that their child has been labeled with Down syndrome. Upon being told their child had Down syndrome, parents struggled with intense feelings, confusion, and disbelief. This was not a joy filled celebration time for parents where they immediately expressed appreciation for this child with Down syndrome. My conversations about appreciation could not have been constructed with these parents at this birthing time.

However, as they began to acknowledge that this child was not what they considered normal or perfect as they had previously imagined, a process of reconstruction or acceptance began. Parents referred to this process as "a gradual process", "totally revamp(ing)", "chang(ing) your ideas on", "restructur(ing) your thoughts", "readapt(ing), refocus(ing), rechang(ing)." Repeatedly parents talked about a process for them where they "learned to accept" this child with Down syndrome for who he/she was. The word "accept" appeared repeatedly as parents, each in their way, eventually said "yes" to this child. This process was different for each parent. Nonetheless, all of the participating parents consistently responded with descriptions of a process they went through in gradually accepting their child with Down syndrome. In the WorldWide Webster Dictionary the word appreciate means to grasp the nature, worth, quality or significance of, to judge with heightened perception or understanding, and to recognize with gratitude. In order for parents to be thankful for or recognize the worth of their child with Down syndrome they appeared to have to let go of the concepts of the perfect or normal child and accept this different child, this child labeled with Down syndrome. Theme one looks at this process of acceptance, this reconstructing process.

The second theme that was analyzed from these conversations concerned experiences parents appreciated describing their child with Down syndrome as a teacher.

Throughout the interviews, parents shared their appreciation for their children as teachers. Parents used words like “I’ve learned”, “he shows us”, “he turned my thoughts”, “he let me see that”, “he’s taught us a lot”, “he’s there to teach you”, “you learn”, “he made us appreciate”, “it’s been rather enlightening”, “I’ve been able to experience whereas I wouldn’t of.” The parents spoke of how their lives had shifted because they took something from their experiences with their children with Down syndrome and learned from them. Parents talked about learning more about humility, patience, loving, compassion, forgiveness, valuing small things, optimism, acceptance of themselves and others, determination, kindness, family relationships, judgements, and selfishness. When people think of teachers, it is not likely that someone with Down syndrome comes to mind. Through these conversations with parents some distinct, appreciative concepts of the experiences of parenting a child with Down syndrome from birth to adulthood have been constructed.

The third theme focused on the role of caregiving and what parents appreciated about that role. For some parents the care was all encompassing and these caregivers shared that the care of their adult child with Down syndrome gave their lives meaning and purpose. As caregivers, some parents appreciated their adult children with Down syndrome remaining in the original family home because they were then companions for them. Parents also appreciated advocating for their children with Down syndrome as part of this caregiver role, and then watching their children succeed in areas they had often never dreamed of. They appeared to appreciate different aspects of their own hard work and how it was connected to their children’s accomplishments.

These three themes fit together to form new meanings of appreciation about life with a child with Down syndrome from birth to adulthood. When children are born with Down syndrome, parents can grow to accept these children (Theme 1) and appreciate them in different ways. One of the ways parents may appreciate their children with Down syndrome is as teachers (Theme 2), appreciating all the unique lessons in life that parents are exposed to because they have children with Down syndrome. Another way parents may appreciate their children with Down syndrome is in their roles as caregivers. (Theme 3) One of the biggest differences in parenting children with Down syndrome may be the number of responsibilities involved in raising this child and a great deal depends on the child's intellectual and physical development. Appreciation for the caregiver role fits with the first theme in that through acceptance of this child, parents are able to appreciate their role as caregiver even if it is over the long term. This long-term caregiver role is often viewed negatively because of the life long responsibilities that so often go with this role.

This research is consistent with Van Riper's (1999) findings to date that indicate "while the birth of a child with Down syndrome involves a 'change of plans' for families, it does not have to be a negative experience. In fact, for many families, it is a positive, growth producing experience" (p.3). My first theme about the process of acceptance or reconstructing fits with Van Riper's idea of how the birth of a child with Down syndrome involves a "change of plans". As well, this study with parents shares how they view that process and what kinds of feelings and adjustments are involved in this change of plans or reconstructing and create a "positive, growth producing experience" or experiences parents appreciate.

Parents in this study indicated that their lives have been enhanced by the experiences involved in raising a child with Down syndrome from birth to adulthood. Many parents said they would now never wish for a child labeled normal, that their lives were somehow better as a result of these experiences. These findings agree with Gath's (1985) where a notable number of families have found their lives were enhanced by what they originally thought was going to be an unbearable burden.

As well, this study adds parents' voices to academic literature; voices Goodey (1991) says have been seldom heard. These voices are from parents of older children and add depth to the voices of parents who have much younger children as in Goodey's book. Finally, this study provides voices of appreciation that need to be heard to balance the dominant cultural constructions about Down syndrome and parenting a child with Down syndrome.

Conclusions of the Study

Three themes were constructed in this study:

- Theme One: Awareness and Acceptance – A Reconstruction Process
- Theme Two: Child as Teacher
- Theme Three: Caregiver Appreciation

These three themes open up spaces for new thinking and add new and different meanings to the concept of Down syndrome and parenting a child with Down syndrome from birth to adulthood. The two simple words "Down syndrome" often conjure up many negative images in the minds of those that hear them. Those images often relate to the dominant bio-medical discourses about Down syndrome where the personhood of the individual with Down syndrome is overlooked. However, these parents' voices together with mine as the researcher, have constructed different images. Parents in this study shared rewarding, joy filled, learning experiences gained from raising a child with Down syndrome. These experiences have continued as this child has grown into adulthood.

The first theme about the reconstructing process of acceptance is important because it suggests that this type of research focusing on appreciation could probably not have been done with new parents of children with Down syndrome. In order to discuss experiences that these parents appreciated, parents went through a process of reconstruction, a gradual process of acceptance of the birth of this child with Down syndrome. In order to look through an appreciative lens, parents in this study needed time, it was a "gradual process" for them to create new meanings for themselves and accept this child with Down syndrome. Once they had accepted this child, something that seemed almost impossible at birth, parents could construct meanings of appreciation with me. The importance of doing this research with parents with adult children is made clear by this parent:

> The rewards I think are much greater now….I wouldn't have ever said that when he was little. I couldn't see past all the fears you have and all the questions you have that you really couldn't answer….I've come to a place of really valuing him in my life versus thinking of him as a burden. I think a lot of parents do that, or you first start off thinking this is a burden and it's a life burden.

In our conversations, parents reflected back on their lives with these children and portrayed their children with Down syndrome as teachers of important lessons, lessons that they appreciated. Many of these lessons were lessons parents learned as their children got older. Children with Down syndrome discussed as teachers is a different perspective and gives new meanings to the label Down syndrome and to the concept of parenting a wise and valued teacher versus parenting a child who is abnormal, disabled, diseased.

Finally, the role of caregiver, a role often looked upon as burden, stress, and long term "perpetual parenthood" was discussed from an appreciative standpoint. Struggles were acknowledged, however, appreciations for the role of caregiver came from a variety of standpoints as parents acknowledged there were many rewards for them. Some parents specifically appreciated that caregiving was long term.

This study has provided alternative portrayals of Down syndrome and the experiences of parenting a child with Down syndrome. In light of these constructions that focus on appreciation there are implications for further research, practice and education.

Limitations of the Study

Disguising subjects in this research project is not without hazards. In order to respect the privacy of the participants, the one female child with Down syndrome was camouflaged in this study. Therefore, in all the transcript quotations used in this thesis paper, the children with Down syndrome are referred to as male. As the researcher I do not think that the concealing of this information has changed any of the core meanings shared. However, I think it is important to mention as a limitation because there are differences in relationships between mothers and daughters, fathers and daughters, mothers and sons and fathers and sons and the use of "my son" versus "my daughter" may influence some of the interpretations of the readers.

Implications for Further Research

This study focuses on experiences parents appreciate in sharing their lives with children with Down syndrome from birth to adulthood. It offers a beginning for further research in adding appreciative voices to dominant forms of discourse on Down syndrome. Research to date suggests that more studies need to be done that focus on resilience, adaptation, and positive aspects of living with a child with Down syndrome. As well, researchers are calling for more research that focuses on real life information instead of simply abstract concepts. Appreciative inquiry, a version of social constructionist inquiry, is a relatively new way of conducting research and focuses on generating new images of social reality. This type of inquiry could be used to fill gaps in the literature on Down syndrome by looking at the positive, resilient, adaptive experiences of living with a child with Down syndrome.

More appreciative inquiry could be used in studies with people who have been labeled with disabilities other than Down syndrome. Wendell (1996) states that there needs to be an understanding of disability that contests dominant discourses and focuses on the strength and capabilities of the disabled. More studies could be done focusing on expanding and challenging some of the social depictions of disability and creating new images of disability.

This research discussed the use and impact of language as a way of constructing meanings together. Focusing on language is another area where much more research could be done. Researchers might look more specifically at how perceptions are formed and interpretations are made as a result of using certain types of words such as disease, normal, healthy, and suffering, relating to people with Down syndrome and other disabilities.

Insight from this study suggests that interesting comparisons could be made between the constructions of people who know someone with Down syndrome personally and the constructions of people who know only the dominant societal depictions of Down syndrome. This could be done with the general public and health professionals to see how these constructions affect an individual's views on abortion of a fetus with Down syndrome.

The literature that was reviewed for this study suggests that there is little research done using people with Down syndrome as the participants. Research could be done that examines what they appreciate in their own lives and what they view as difficulties or burdens.

This research indicates that we are only beginning to discover the many areas where studies could be conducted regarding genetic testing. With the information about genetics inundating the medical community and the public at large, more studies could be done looking at how parents and health professionals view genetic testing and how far they think testing should go. There are many areas where researchers could focus their attention. Ethical issues, the notion of eugenics and prenatal testing, and the concept of producing the ideal human being are examples of potential areas of study.

Implications for Practice

Parents involved in this study gave birth to their children with Down syndrome twenty to forty years ago. Although support for parents and their children with Down syndrome has increased dramatically since that time, negative depictions of Down syndrome persist. With the increasing opportunities for genetic testing, many prospective parents are now faced with difficult decisions, decisions prospective parents were never faced with in the past. Research to date suggests that prospective parents need to be provided with:

- A clearer understanding of genetic testing procedures and test results.
- All of the options available to them if a prenatal diagnosis is positive.
- More opportunities for counselling and support. (Pueschel, 1991; Spudich, 1992; Statham and Green, 1993; Blumberg, 1994; Elkins, Stovall, Wilroy, and Dacus, 1986; Stein 1997; and Helm, Miranda, and Chedd, 1998)

In the study done by Helm et al.(1998), ten mothers who had received a prenatal diagnosis of Down syndrome, repeatedly stressed that it was incumbent on health professionals to present all options available to parents in an open-minded way and to provide current and up-to-date information. They stated that negative terminology or accentuation of difficulties was quite unhelpful. These same mothers consistently stated that they had felt unsupported in arriving at their decision to keep their fetuses with Down syndrome because health professionals were overtly or covertly advocating from their own point of view. Although these mothers' experiences with health professionals varied and some were positive and reassuring, all of the mothers in this study reported meeting with some health care professionals, including obstetricians, nurses, technicians, and genetic counselors that did not support their choice to continue the pregnancy.

Even though genetic counselors are currently trained to be nondirective, Burke and Kolker's (1994) findings support that the ethos of nondirectiveness in genetic counselling is tested in real-life situations. In their final analysis, they suggest that the principle of nondirectiveness in genetic counselling is frequently challenged. Counselors in their study talked about making their own judgments about a client's capacity for absorbing information under stressful conditions. It was not considered that it might be directive for the counselor not to share all pertinent information with the client. Nor was it considered directive to share one's personal opinion. Pueschel (1991) states:

> Counselors must realize that no message provided to parents is value-free….If factual information, various options, and guidance are sensitively provided by counselors, parents will be able to make independent decisions based upon the knowledge they have gained through the genetic counseling process.(pp.189-190)

In order for prospective parents to make fully informed decisions with clarity, health professionals must be willing and able to share with prospective parents all the options available and then respect and support parents' final decisions. Prospective parents need to be provided with an understanding of the current general prognosis for children with Down syndrome, but also the understandings discussed in this thesis - that parenting a child with Down syndrome may also bring joys and rewards. One mother in this study shared her thoughts:

> And I think a lot of people probably make that decision to do that (abort) out of ignorance, you know, through no fault of theirs and out of being frightened and the unknown and all the rest and I think it's a shame because people need to know all the joys attached with it. You know, instead of the stigma and that this horrible thing has happened….It doesn't take very long and you start experiencing all the wonderful parts of a baby like that….It's very satisfying….I think I could probably adopt ten other Down syndrome kids, if I had the energy I probably would.

It has been suggested by Palmer et al. (1993), Blumberg (1994), and Helm et al. (1998), that parent-to-parent referrals are one of the most effective ways a health professional can provide prospective parents with information on what it might be like to parent a child with Down syndrome. Although these referrals by health professionals appear to be occurring in some prenatal counseling situations, these referrals could happen more consistently and become part of regular prenatal counseling procedure when parents have received a prenatal diagnosis of Down syndrome. Elkins et al. (1986) suggests standardized guidelines for prenatal counselling could be put into place that would be acceptable to both parents and professionals.

This most critical sharing of information between prospective parents and parents who already have children with Down syndrome would involve prospective parents in very different discussions than those they would have with health professionals because other parents would be sharing their life experiences with a child with Down syndrome. When prospective parents are making life and death decisions, other parents may prove to be invaluable sources of information because they have been there and experienced what life is like with a child with Down syndrome. However, if direct access to other parents was not available, parents could be provided with current reading or video material that focuses on parent/child relationships. Information from this study, these parents' voices could be used to share information about appreciation.

Since genetic counselling is still a relatively new and growing field, health professionals, especially physicians are often the ones involved in handling issues spawned by genetic testing. It is important that both counselors and health professionals be aware of how dominant forms of discourse regarding Down syndrome may inform prospective parents' decisions and their own counseling procedures. Reflective practices and questions could be used as a means to create room for consideration of other possibilities.

Implications for Education

This research indicates that there is much work to be done in educating the general public and health professionals about new and fuller portrayals of persons with Down syndrome. The Down Syndrome Research Foundation is in the process of creating pamphlets and a CD that will be available for health professionals and prospective parents. This study could provide more material for pamphlets, videos or posters and share appreciative quotes directly from these parents who have adult children with Down syndrome.

Today, people with Down syndrome are steadily integrating into the mainstream world. However, letting go of the dominant cultural constructions of someone with

Down syndrome is something that will be helped through education. Medical, counselor, and educational training could include more direct contact with people with Down syndrome and other disabilities for students in these disciplines to begin to get beyond labels and see actual people instead. Core curriculum courses could be offered that specifically focus on experiential work with people with Down syndrome or with other disabilities. Blumberg (1994) suggests that all genetic counselors as part of their specialized training should be involved in an activity that will give them contact with persons with disabilities in non-medical settings.

In conclusion, this study has offered the "glass half full" perspective. In conversations with these parents, they shared a wide range of experiences they appreciated having lived with a child with Down syndrome from birth to adulthood. This research is about how parents said "yes" to a child when the child was born with Down syndrome, how they have constructed concepts of appreciation even though the dominant articulations about Down syndrome are rooted in pathology and deficit. This research gives another perspective, that a child with Down syndrome can be celebrated and enjoyed. Through challenging taken-for-granted assumptions and constructing new meanings by sharing conversations about experiences parents appreciated living with a child with Down syndrome from birth to adulthood, parents have been able to share elements of human possibilities that might have otherwise gone unheard. These possibilities need to be shared to help create a larger base of information that can be used by health professionals in their encounters with prospective parents in society at large.

REFERENCES

American Association on Mental Retardation. (1992). Mental retardation: Definition classification, and systems of supports. (On-line). Available: http://thearc.org/gaindex.html.

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington: Author.

Anderson, R., & Bury, M. (1988). Living with chronic illness: The experience of patients and their families. London: Unwin Hyman.

Asch, A., & Fine, M. (1988). Shared dreams: A left perspective on disability rights and reproductive rights. In M. Fine & A. Ashe (Eds.). Women with disabilities (pp. 297-305). Philadelphia: Temple University Press.

Association for Retarded Citizens, (1992). Introduction to mental retardation. (On line). Available: http://thearc.org/gaindex.html.

Berube, M. (1996). Life as we know it. Toronto: Random House of Canada Limited.

Bjerklie, D., Dorfman, A., Gorman, C., & Nash, J. M. (1994, January 17). The genetic revolution. Time, pp.40-47.

Blendon, R. J., Benson, J. M., & Donelan, K. (1993). The public and the controversy over abortion. Journal of the American Medical Association, 270, 2871-2876.

Blumberg, L. (1994). The politics of prenatal testing and selective abortion. Sexuality and Disability, 12 (2), 135–153.

Bogdan, R.C., & Biklen, S.K. (1982). Qualitative research for educators: An introduction to theory and methods (2nd ed.). Toronto: Allyn and Bacon Inc.

Botkin, J. R. (1995). Fetal privacy and confidentiality. Hastings Center Report, 25, 32-39.

British Columbia's Premier Forum. (1994). Persons with Disabilities: Directions for dignified and independent living. (Background Paper 5).

Burke, B. M., & Kolker, A. (1994). Directiveness in prenatal counseling. Women and Health, 22 (2), 31-53.

Bushe, G.R. (1995). Advances in appreciative inquiry as an organization development. Organization Development Journal, 13 (3), 14-22.

Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 597-604.

Clarke, A.D.B., & Clarke, A. M. (1996). The historical context. In B. Stratford & P. Gunn (Eds.), New approaches to Down syndrome (pp.12-23). New York: Cassell.

Coleridge, P. (1993). Disability, liberation and development. UK: Oxfam.

Conley, R. W. (1985). Down syndrome: Economic burdens and benefits of prevention. In V. L.Dellarco, P. E. Voytek, & A. Hollaender (Eds.), Aneuploidy : Etiology and mechanisms (pp. 35-73). New York: Plenum Press.

Cooperrider, D. L. (1998). Appreciative inquiry. In S.A. Hammond & C. Royal (Eds.), Lessons from the field (p.12). Plano, TX: Practical Press Inc.

Cooperrider, D. L., & Srivastva, S. (1987). Appreciative inquiry in organizational life. In R. Woodman & W. Pasmore (Eds.) Research in Organization Change and Development: Volume 1 (pp.129-169). Greenwich, CT: JAI Press.

Cunningham, C. (1998). Families of children with Down syndrome. Down Syndrome: Research and Practice, 4, 87-95.

Dahl, M. (1993). The role of the media in promoting images of disability – disability as metaphor: The evil crip. Canadian Journal of Communication, 18, 75-80.

Elkins, T. E., Stovall, T. G., Wilroy, S., & Dacus, J. V. (1986). Attitudes of mothers of children with Down syndrome concerning amniocentesis, abortion, and prenatal genetic counseling techniques. Obstetrics and Gynecology, 68, 181-184.

Elkins, T. E., & Brown, D. (1995). Ethical concerns and future directions in maternal screening for Down syndrome. Women's Health Issues 5 (1), 15-20.

Ernest, P. (1995). The one and the many. In L. Steffe & J. Gale (Eds.). Constructivism in education (pp. 459-486). New Jersey: Lawrence Erlbaum Associates, Inc.

Finnegan, J. (1991). Prenatal diagnosis and pregnancy outcomes: Special needs adoption. The Genetic Resource, 6, 33-39.

Fletcher, J. (1973). Ethics and euthanasia. American Journal of Nursing, 73, 670-675.

Foucault, M. (1977). The history of sexuality: Volume I. New York: Pantheon.

Gath, A. (1985). Parental reactions to loss and disappointment: The diagnosis of Down's syndrome. Developmental Medicine and Child Neurology, 27, 392-400.

Gergen, K. (1982). Toward transformation in social knowledge. New York: Spring-Verlag.

Gergen, K. (1990). Affect and organization in postmodern society. In S. Srivastva & D.L.Cooperrider (Eds.), Appreciative management and leadership (pp. 153–174). San Francisco: Jossey-Bass.

Gergen, K. (1994). Realities and relationships. Cambridge: Harvard University Press.

Gergen, K. (1999a). Constructionist dialogues and the vicissitudes of the political. Draft copy for volume edited by I. Velody for Sage London. (On-line). Available: http://www.swarthmore.edu/SocSci/kgergen1/text7.html.

Gergen, K. (1999b). Social psychology as social construction: The emerging vision. The message of social psychology: Perspectives on mind in society. (Eds.) C. McGarty and A. Haslam. Oxford: Blackwell. (On-line) Available: http://www.swarthmore.edu/SocSci/kgergen1/text1.html.

Gilgan, J. F. (1993). Publishing research reports based on qualitative methods. Marriage and Family Review, 18, 177-181.

Glover, N. M., & Glover, S. J. (1996). Ethical and legal issues regarding selective abortion of fetuses with Down syndrome. Mental Retardation, 34 (4), 207-214.

Goodey, C.F. (Ed.). (1991). Living in the real world. London, England: Twenty-One Press.

Government Affairs Office. (July, 1998). Summary. Abstract from: White paper on mental retardation v. developmental disabilities should the Arc change its focus from serving people with mental retardation to serving people with all developmental disabilities. (On-line). Available: http://thearc.org/gaindex.html.

Grant, G. (1986). Older carers, interdependence and the care of mentally handicapped adults. Aging and Society, 6, 333-351.

Guba, G. E., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry. Educational Communication and Technology - A Journal of Theory, Research, and Development, 30 (4), 233-252.

Guba, G. E., & Lincoln, Y. S. (1989). Fourth generation evaluation. Newbury Park: CA: Sage Publications.

Heller, T. (1993). Aging caregivers of persons with developmental disabilities: Changes in burden and placement desire. In K.A. Roberto (Ed.), The Elderly Caregiver (pp. 21-39). Newbury Park: Sage Publications.

Helm, D. T., Miranda, S., and Chedd, N. A. (1998). Prenatal diagnosis of Down syndrome: Mothers' reflections on supports needed from diagnosis to birth. Mental Retardation, 36 (1), 55-61.

Hook, E. B. (1994). Screening for Down's syndrome (J. G. Grudzinskas, T. Chard, M. G. Chapman, H. S. Cuckle, Eds.). Cambridge: Cambridge University Press.

Hunt, N. (1967). The world of Nigel Hunt. England: Darwen Finlayson Ltd.

Ingstad, B., & Whyte S. R. (Eds.). (1995). Disability and culture. Los Angeles: University of California Press.

Jennings, J. (1987). Elderly parents as caregivers for their adult dependent children. Social Work, 32, 430-433.

Key, S. W., & Lindgren, M. (1999). Improved fetal screening for Down syndrome. Women's Health Weekly, 13-15.

Kingsley, J., & Levitz, M. (1994). Count us in. New York: Harcourt Brace & Company.

Kliewer, C. (1998). Schooling children with Down syndrome: Toward an understanding of possibility. New York: Teachers College Press.

Kolker, A., & Burke, B. M. (1987). Amniocentesis and the social construction of pregnancy. Alternative Health Maintenance and Healing Systems for Families, 95-114.

Kolker, A., & Burke, B. M. (1993). Deciding about the unknown: perceptions of risk of women who have prenatal diagnosis. Women and Health, 20 (4), 37-56.

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. The American Journal of Occupational Therapy, 45, 214-222.

Kupperman, M.,Golberg, J.D., Nease, R.F., Washington, A. (1999). Who should be offered prenatal diagnosis? The 35-year-old question. American Journal of Public Health, 89 (2), 160-164.

Kvale, S. (1996). Interviews. Thousand Oaks: Sage Publications.

Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park: Sage.

Lusthaus, E. W. (1985). Involuntary euthanasia and current attempts to define persons with mental retardation as less than human. Mental Retardation, 23, 148-154.

McDonough. P. (1990). Congenital disability and medical research: The development of amniocentesis. Women and Health, 16, 137-153.

McLaren, A. (1990). Our own master race. Toronto: McClelland & Stewart, Inc.

Murphy, E. (1997). Constructivist epistemology. (On-line). Available: http://www.stemnet.nf.ca/~elmurphy/emurphy/clee2.html

Murphy, R. (1995). Encounters: The body silent in America. In B. Ingstad & S. R. Whyte (Eds.), Disability and culture (pp.140-159). Los Angeles: University of California Press.

National Down Syndrome Society, (November 25,1996). Parent and professional information. (On-line). Available: http://www.ndss.org/gen.html#resource.

Palmer, S., Spencer, J., Kushnick, T., Wiley, J., Bowyer, S. (1993). Follow up survey of pregnancies with diagnoses of chromosomal abnormality. Journal of Genetic Counseling, 2 (3), 139–152.

Palys, T. (1992). Research decisions. Toronto: Harcourt Brace Jovanovich Canada Inc.

Plager, K. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.), Interpretive phenomenology (pp. 65-85). Thousand Oaks: Sage Publications.

Pueschel, S. M. (1991). Ethical considerations relating to prenatal diagnosis to fetuses with Down syndrome. Mental Retardation, 29, 185-190.

Roberto, K. A. (1993). Elderly caregiver: Caring for adults with developmental disabilities. Newbury Park: Sage Publications.

Sadovnick, A. D., & Baird, P. A. (1981). A cost-benefit analysis of prenatal detection of Down syndrome and neural tube defects in older mothers. American Journal of Medical Genetics, 10, 367–378.

Saxton, M., Anderson, B., & Blatt, R. J. R. (1991). Prenatal diagnosis and pregnancy options: Continuing the pregnancy. The Genetic Resource, 1, 33-35.

Segal, J. (1986). Winning life's toughest battles: Roots of human resiliency. USA: Ivy Books.

Seltzer, M. M., Krauss, M. W., & Tsuenmatsu, N. (1993) . Adults with Down syndrome and their aging mothers: Diagnostic group differences. American Journal of Mental Retardation, 97 (5), 496-508.

Spudich, H. (1992). Looking for answers, finding more questions: Report on the Vancouver workshop on bioethical issues. Brussels: International League of Societies for Persons with Mental Handicap.

Statham, H., & Green, J. (1993). Serum screening for Down's syndrome: Some women's experiences. British Medical Journal, 307, 174-176.

Steele, J. (1996). Epidemiology: Incidence, prevalence and size of the Down's syndrome population. In B. Stratford & P. Gunn (Eds.), New approaches to Down syndrome (pp. 43-45). New York: Cassell.

Stein, M.T. (1997). Responding to parental concerns after a prenatal diagnosis of Trisomy 21. Journal of Developmental and Behavioural Pediatrics, 18, 42-46.

Stein, Z., Susser, M., & Guterman, A. V. (1973). Screening program for the prevention of Down's syndrome. The Lancet, I, 305-310.

Stratford, B. (1991). Human rights and equal opportunities. International Journal of Disability, Development and Education, 38 (1), 3-13.

Stratford, B. (1994). Down syndrome is for life. International Journal of Disability, Development and Education, 41 (1), 3-13.

Stratford, B. (1996). In the beginning. In B. Stratford & P. Gunn (Eds.), New approaches to Down syndrome (pp.1-3). New York: Cassell.

Taylor, S., & Bogdan, R. (1984). Introduction to qualitative research methods (2nd ed.). New York: John Wiley and Sons.

Trainer, M. (1991). Differences in common. MD: Woodbine House.

Trumble, S. (1997). How to treat people with Down syndrome. (On-line). Available: http://www.downsyndrome.com/treatds.htm

van Manen, M. (1990). Researching lived experience (1st ed.). London, Ontario: The Althouse Press.

van Manen, M. (1997). Researching lived experience (2nd ed.). London, Ontario: The Althouse Press.

Van Riper, (1999). Living with Down syndrome: the family experience. Down Syndrome Quarterly, 4, 1-7.

Wendell, S. (1996). The rejected body. NY: Routledge.

White, M.T. (1999). Making responsible decisions: An interpretive ethic for genetic decisionmaking. Hasting Centre Report, 29 (1), 14-22.

Williams, P. (1995). Should we prevent Down's syndrome? British Journal of Learning Disabilities, 23, 46-49.

Williams, S. J. (1989). Chronic respiratory illness and disability: A critical review of the psychosocial literature. Social Science and Medicine, 28, 791-803.

Wong, B. & McKeen, J. (1998). The new manual for life. Gabriola Island, BC: PD Publishing.

World Health Organization. (1980). International classification of impairments, disabilities, and handicaps. Geneva: Author.

Appendix A

Medical Information regarding Down syndrome

Down syndrome is usually caused by an error in cell division known as nondisjunction. Nondisjunction is a faulty cell division that results in an embryo with three number 21 chromosomes instead of two. Ninety-five percent of all cases of Down syndrome occur because of nondisjunction. Today, Down syndrome is often referred to as "trisomy 21" simply because there are most often three copies of the 21st chromosome.

Two other types of chromosomal abnormalities, mosaicism and translocation, are also implicated in Down syndrome. In mosaicism, nondisjunction of the number 21 chromosome occurs after fertilization. Therefore, there is a mixture of two types of cells, some containing 46 chromosomes and some containing 47. This creates a mosaic pattern and thus the term "mosaicism" is used. Mosaicism is rare, and is only responsible for 1 to 2 percent of all cases of Down syndrome.

Translocation occurs when part of the number 21 chromosome breaks off during cell division and attaches to another chromosome. The total number of chromosomes remains 46; however, the presence of an extra part of the number 21 chromosome causes Down syndrome. This type of chromosomal change occurs in only 3 to 4 percent of people with Down syndrome (personal communication, National Down Syndrome Society, November, 1996).

Appendix B

Definition of Mental Retardation and Developmental Disability

According to the American Association on Mental Retardation (AAMR):

> an individual is considered to have mental retardation based on the following three criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skill areas; and the condition is present from childhood (Defined as age 18 or less. (AAMR, 1992)

Adaptive skill areas include ten adaptive skills: communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics, community use and work.

The Diagnostic and Statistical Manual of Mental Disorders (4th edition) (1994) bases its definition of mental retardation on three diagnostic features. The essential feature of mental retardation or criterion one, is significantly subaverage general intellectual functioning. This subaverage general intelligence must exist along with criterion 2, significant deficits in adaptive behaviour, and criterion 3, it must manifest before adulthood, or before age eighteen. The use of standardized IQ tests is still used to determine intellectual functioning. The intelligent quotient or IQ of an individual is obtained by administering one or more standardized tests such as the Wechler Intelligence Scales for Children – Revised, the Stanford-Binet, or the Kaufman Assessment Battery for Children. Four levels of mental deficiency have been recognized by the DSM-IV and are rated according to IQ ranges. However, the diagnosis for mental retardation must also include deficiencies in adaptive behaviour.

The four degrees of severity of mental retardation are described as follows: Mild Mental Retardation (50-55 to 70 IQ), Moderate Mental Retardation (35-40 to 50-55 IQ), Severe Mental Retardation (20-25 to 35-40 IQ), and Profound Mental Retardation (Below 20-25 IQ) (American Psychiatric Association, 1994). The American Association on Mental Retardation (AAMR) no longer label individuals according to the categories of mild, moderate, severe and profound mental retardation based on IQ level. Instead, it looks at the intensity and pattern of changing supports needed by an individual over a lifetime. However, several articles and books still use the terms "mild", "moderate", "severe", and "profound", when referring to mental retardation.

Many people who think that the term "developmental disabilities" is simply a politer way of referring to "mental retardation" do not realize that the terms are defined differently. People referred to as having a developmental disability may also be referred to as mentally retarded. However, being referred to as mentally retarded does not automatically mean you are also developmentally disabled. Federally defined, people with developmental disabilities are at least five years of age with a mental and/or physical impairment that occurred before they turned 22 years of age. This mental and/or physical impairment must limit them in at least three of seven major life activities. Eighty-seven percent of people with mental retardation have mild mental retardation. Unless they have a second disability, people with mild mental retardation may not have limits in three of the seven major life activities (Government Affairs Office, July 1998).

Appendix C

Amniocentesis, CVS, and Triple Marker Screening

Amniocentesis, generally performed by collecting amniotic fluid using a needle passed through the mother's abdominal wall into the amniotic sac surrounding the baby. The fluid contains foetal cells shed by the fetus and these are cultured and their chromosomes examined to detect fetal abnormalities. Whilst amniocentesis is a well-established prenatal diagnostic procedure, developments continue to be made, particularly in how quickly results are obtained.

Chorionic villus sampling (CVS) is a later development and usually performed between 8 and 11 weeks of gestation, thereby giving parents an earlier opportunity to decide about a positive prognosis. It involves taking a villus (placental tissue) sample at the point where the placenta attaches to the uterine wall. Genetic abnormalities are often reflected in this tissue. Like amniocentesis there is a small risk of miscarriage after the procedure (Steele, 1996; Glover & Glover, 1996). Previously in BC, only women thirty-five years of age or older were offered prenatal diagnostic testing, amniocentesis or CVS.

However, over the last ten years there have been considerable developments in maternal blood tests for Down syndrome. These tests do not give a definite answer through analysis of foetal cells, but indicate the level of risk of having an affected pregnancy by establishing the levels of certain proteins in the blood. Currently, all women in BC, regardless of their age, are offered Maternal Serum Screening also known as Triple Marker Screening. This prenatal screening test is offered during the second trimester of pregnancy and tests maternal blood for abnormal levels of three biochemical markers – alphafetoprotein (AFP), chorionic gonadotrophin (hCG), and unconjugated estriol. A low level of AFP, unconjugated estriol, and a high level of hCG are associated with an increased probability for Down syndrome. Women who screen "positive" with the triple marker test are then eligible for amniocentesis or CVS. Younger women, where the majority of Down syndrome births occur, now have access to a prenatal screening procedure (Steele, 1996).

Currently, there are studies underway that are looking at a combination of blood tests and high definition ultrasound in fetal screening for Down syndrome (Key & Lindgren, 1999).

Appendix D

Dimensions of Sample

Dimensions of Sample

Participant	Gender	Ethnicity	Race	Family Income	Parent Education Level	Parents' Health Status/ Age	Number of Children in Family	Age of child with Down syndrome	Sibling Ages	Living at Home Yes/No	Employed Yes/No	Occupation
1 & 2	Female & Male	Canadian	Caucasian	$75,000	Female - B.A. --------- Male - 2 yrs. Univ.	Good ----------- 50's	2	21	24	No ----------- Caregivers	Yes 1 day ----------- Day Program	Vacuuming ----------- Recreation Centre
3 & 4	Female & Male	English	Caucasian	above $60,000	Both High School	Asthma Back Operations ----------- 70's	3	33	52, 48	No ----------- Caregivers	No ----------- Day Program	
5 & 6	Female & Male	Irish	Caucasian	$18,500	Female High School --------- Male Technical Tr.	Good ----------- 80's	3	40	49, 47	Yes	No ----------- Day Program	
7	Female	English	Caucasian	$30,000 to $50,000	B. Ed. Degree	Good ----------- 70's	5	28	51, 49, 45, 38	Yes ------------ Own Attached Apartment	No ----------- College	Job Placement ----------- Video Store
8	Female	Irish English Scottish	Caucasian	above $75,000	High School- Some college	Excellent ----------- 50's	4	19	23, 23, 15	Yes	No ----------- Post Secondary	Job Placement ----------- Motel
9	Female	English/ Swiss	Caucasian	$30,000 to $50,000	High School	Good ----------- 47	4	29	27, 24, 22	Yes ------------ Own Attached Apartment	No	At home

Appendix E

Letter of Introduction

Consent Form

Letter of Introduction

Dear ____________,

My name is Susanne Muirhead and I am currently working on my Master's Degree in Educational Counselling at the University of Northern British Columbia. I have had an ongoing interest in Down syndrome since I was a very young girl, as I grew up with an older brother with Down syndrome. As well, my experiences with my brother continued when he moved to Prince George and lived here independently for more than eight years. I worked with him on a weekly basis, completing his budget and as family members we did a great deal together socially. The research I have chosen to undertake involves looking at the experiences parent caregivers appreciate about living with a child with Down syndrome from birth through to adulthood.

The study will consist of two formal conversations, each lasting approximately one to two hours. As well, I will contact you by phone or in person if there is any reason that I may need some clarification on the conversations.

This research is completely voluntary. If you agree to participate I will ask that you fill out the attached "Consent Form" and return it to me personally. I will then set up an interview time and place that is comfortable, private and convenient to you.

If you have any questions please contact me at 250-562-3232, or one of my thesis supervisors, either Professor Glen Schmidt at 250-960-6519 or Dr. Colleen Haney at 960-5639. I look forward to your assistance in this research study.

Sincerely,

Susanne Muirhead

Consent Form

Title of Project:
Appreciating Adult Children with Down Syndrome

I, _________________________ hereby give my consent to participate in this study. I understand that the purpose of this research is to explore the experiences that parents appreciate about living with a child with Down syndrome from birth to adulthood. This study will be conducted by talking to individual parents who have an adult child with Down syndrome.

Susanne Muirhead has informed me that this research forms a component of her Master's Degree in Educational Counselling at the University of Northern British Columbia. This study is being supervised by Professor Glen Schmidt.

If I agree to participate in this study, Susanne Muirhead will arrange interview times and places at my convenience. I agree to take part in two discussions and they will each take approximately one to two hours. I agree to allow them to be audiotaped and transcribed. I am aware that all conversations will be kept strictly confidential and only Susanne Muirhead will have access to the tapes. I understand that all the interview material will be coded by Susanne Muirhead to ensure anonymity and all audiotapes will be destroyed upon the completion of her thesis.

If I agree to participate in this study, I understand that I may still withdraw at any time. If I have any questions or concerns, I know I can contact Susanne at 250-562-3232, Professor Glen Schmidt at 250-960-6519.

Your signature below indicates that you have read and understand the above information and consent to participate in this research study. Please sign two copies and keep one for your records. Thank you for your time and your assistance.

Name: __________________________ **Signature:** ____________________

Date: ___________________________ **Witness:** ____________________

Appendix F

Interview Guide

Interview Guide

- Introduce and review the purpose of the research.

- Discuss confidentiality and voluntary nature of participation.

- Explain the audio recording procedure and give assurance that the tape recorder may be turned off simply by his or her request.

- Obtain signed consent for the interviewing.

Keep in mind the research question:

What experiences do you appreciate as a parent in regards to living with a person with Down syndrome from birth to adulthood?

Sample questions and probes that may be used in the interview in order to elicit information –

- As you think back, can you think about and then share some of your most memorable moments, moments when you really appreciated being a parent of a child with Down syndrome?
- What rewarding experiences stand out for you since you began parenting a child with Down syndrome?
- How did you feel experiencing that moment?
- Why are these moments meaningful to you?
- How has your role as caregiver shifted over the years and is there any appreciation about those shifts?
- How have these experiences affected you as a person?
- What experiences might you share with someone who has just had a child with Down syndrome?
- What would you miss most if you had never been a parent of a child with Down syndrome?
- How does your experience of being the parent of a child with Down syndrome equate with the experiences you anticipated or you were told to anticipate?
- Is there anything else you would like to add to your list of experiences?
- Thank the participant for their participation in the research and remind them about taking part in a follow up interview once the first interview has been transcribed and analyzed. Explain that the second interview will be for the purpose of validating the interpretation of the conversations and to make any changes necessary to fit with their views as the participants.