Perspectives of Mothers with Developmental Disabilities: The Same Dreams, The Same Goals, The Same Disappointments

by

Kelly Fells
B.A., University of Victoria, 1989

A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF ARTS

in the Faculty of Human and Social Development,
School of Child and Youth Care

[redacted] We accept this thesis as conforming
o the required standard

Dr. Carol Stuart, Supervisor (School of Child and Youth Care, Ryerson Polytechnic University)

[redacted]

Dr. Frances Ricks, Supervisor (School of Child and Youth Care)

[redacted]

Dr. Michael Prince, Outside Member (Faculty of Human and Social Development)

[redacted]

Dr. G. Hartrick, External Examiner (School of Nursing)

University of Victoria

Supervisors: Dr. C. Stuart, Dr. F. Ricks

ABSTRACT

There is a limited literature base with regards to families headed by parents with developmental disabilities, and even less on the subjective experiences of mothers with developmental disabilities. Therefore, policy and program development are largely grounded in 'outsider' information. Using an ethnographical inquiry as a guide, this study examined how mothers with developmental disabilities make sense of their parenting roles. The goal was to understand what these parents identified as key issues, and whether their experiences and understanding of the parenting roles were ontologically based. Two participants were individually interviewed and the transcribed interviews, along with field notes were analyzed for relevant themes. Two key factors relevant to understanding the standpoint of mothers with developmental disabilities were identified:

1. The ways in which parents with developmental disabilities make sense of their parenting role seem to be shaped by societal norms and cultural expectations, therefore it is not surprising that their experiences as parents parallel those of the dominant culture. However, society's institutions insist on making mothers with developmental disabilities different by virtue of their disability and imposing different standards, for example, to receive service they must have an IQ score that falls below the norm, rather than an assessment of individual parenting skills.
2. In addition to individual and familial characteristics, parenting is affected by the systemic influences of social, economic and educational environments, including the inter-related themes of poverty, literacy and life skills training. This thesis concludes by

examining the implications of the participants' perspectives for program delivery and suggesting areas for further research.

[redacted]

Dr. Carol Stuart, Supervisor (School of Child and Youth Care, Ryerson Polytechnic University)

[redacted]

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[redacted]

Dr. Michael Prince, Outside Member (Faculty of Human and Social Development)

[redacted]

Dr. Gwen Hartrick, External Examiner (School of Nursing)

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Acknowledgements

I would like to thank the two women in this study who were willing to share some of their parenting experiences and time with me.

I would also like to thank my supervisor, Dr. Carol Stuart, for her willingness to be an involved mentor despite her decision to leave her position at the University of Victoria for one at Ryerson University -- a decision made even before we began working together. Carol's thoroughness, observations, support and patience will always be remembered and appreciated! I would also like to thank my committee for their interest, encouragement and assistance in this project.

In addition, I would like to acknowledge the wonderful support and feedback of my mentor and friend of twenty years, Karen Hallam. I am also thankful to Carlos Moniz, my family and my friends for their faith in me, their refusal to let me give up, and especially for their patience when it was just plain difficult to be around me.

Dedication

I would like to dedicate this thesis to my ‘DOD’ (Dear Old Dad). Without his support and prodding to attend college and then university, I would not have completed this degree.

Chapter One: Introduction

Prologue

Sitting on a couch in her two-bedroom apartment, Ann spoke about life since becoming a mother. Contending with the daily routines familiar to most parents of young children, she gets her three and seven year old daughters up in the morning, makes their breakfast and then walks the oldest, Sherri, to school after Karen has been dropped off at her preschool. Ann spends her days catching up with household chores, volunteering at the preschool, visiting old friends, or watching her favorite soaps. What is perhaps unusual about Ann's story is that she has a developmental disability, also known as a cognitive disability, or a mental handicap.

A friendly, candid woman in her mid-thirties, Ann does not dismiss the fact that she has a developmental disability, but does not view it as the key factor in her experience as a mother. Rather, Ann feels it was the influences of her childhood, the support she received, and the consequences of poverty, that have most profoundly affected her parenting experience.

It was not long after Ann met her partner Rob eight years ago, "... and without even really trying," that she became pregnant with Sherri. Thrilled with the news of the pregnancy, Ann admits to feeling a little smug that the extended families initial misgivings have since been proven wrong. It was the couple's financial instability and their decision not to get legally married that continues to be of concern to the families.

Ann speaks in glowing terms of her daughters' accomplishments, the importance of structure and consistency (and not always being able to provide it), and the love that *she has for them. However, she is also quick to acknowledge that parenting has its down sides as well. The challenge of managing on a disability cheque and Rob's minimum wages has meant that adequate food and housing are frequent sources of anxiety. She also worries that her tolerance level is at times insufficient to deal with the children's incessant vying for her complete and total attention.*

When the girls reached two and five years of age, Ann recalls feeling overwhelmed with everything. Responsibilities she had felt competent in earlier on were now more difficult to manage. It seemed that the demands of parenting had intensified along with the girls' quests for autonomy. She tried to ignore the fear that "I might lose my children if I admitted I needed help..." just like one of her friends. Ann explained to her social worker that she was having some difficulties and needed assistance getting back on track. Within a few weeks of her social worker's referral to a community agency, a Parent Support Worker (PSW) and Ann had began identifying and working on certain aspects of her parenting skills.

While not all of Ann's goals were the same as the ones identified by her social worker and the PSW, they were goals she believed were relevant for her family, and goals she was committed to working on. While a tidy home and a balanced budget were not a priority for Ann, learning how to help her children build friendships, plan for family activities and maintain good communications with the schools, were. After eighteen months of home visits, Ann informed her PSW and social worker that she had accomplished her goals and no longer required the PSW's involvement on a regular basis.

While it is every parent's right to decide how much support they are willing to accept, (unless there are child protection authorities involved), the sad reality is that there are many children, those with and without parents who have developmental disabilities, who are receiving less than satisfactory care despite various interventions. The dilemma faced by many professionals who support parents with developmental disabilities is how to reconcile the "gray areas" of parenting. Obviously there are safety aspects to caring for children that are non-negotiable, but what about parenting skills that are comprised of cultural judgements about what constitutes "adequate" standards of care? Could more collaborative, effective learning occur with a closer examination of what mothers with developmental disabilities identify as key issues in parenting?

(The family in this vignette was not intended to reflect the stories of either of the two participants from this study.)

Introduction

Raising children is probably the most complicated and challenging of the tasks faced by families: It is a responsibility that involves the shaping of values, knowledge and skills. For those populations, who are ignored or deemed unfit by the rest of society, this task also includes the responsibility to manage issues related to poverty and the stereotypes of mainstream culture. With the stresses of modern day living and children's increased exposure to the conflicts of our world, the demanding work of child rearing is now more complex than ever before. Parenting is equivalent to nothing else we do in terms of consequence and perpetuity.

Many parents find themselves ill-prepared for the role despite everything they have read, previous babysitting experience, courses they may have taken, or even with the subtle preparation that is passed from parent to child. It is likely that the developmentally disabled mother facing the world of child rearing will be doing so with very little preparation. Typically, she has not taken prenatal or parenting classes, nor has she read parenting books and magazines since these are designed for people who have: a) adequate levels of reading comprehension, b) the financial ability to pay for courses and texts, and/or c) the cognitive ability to keep up with the faster pace of generic parenting programs (Campion, 1995).

Women who are labeled developmentally disabled often live in poverty and, due to a variety of individual and cultural conditions, may face unique obstacles (Espe-Sherwindt & Crable, 1993). Typically, the developmentally disabled individuals' learning needs have not been met in school, by family, or by the larger culture. As well, developmentally disabled women often experience rejection and isolation from natural support networks, a response to the common perception that persons with developmental disabilities are "abnormalities," and destined to be cared for in group homes or by aging parents (Llewellyn, McConnell, Cant, & Westbrook, 1999). Just as with many non-disabled cultures, the road to independence attracts those with developmental disabilities and sometimes leads to marriage and/or parenthood, regardless of whether "ideal" parenting conditions are present. Indications of a growing number of parents with developmental or other learning disabilities are disconcerting, considering that few resources currently exist to assist parents in dealing with the difficulties often associated with parenting (Tymchuk, 1990; Espe-Sherwindt & Crable, 1993).

Developmental Disabilities as a Social Construction

Definitional uncertainty

A wide variety of terms, including "feebleminded," "mentally handicapped," "intellectually and cognitively limited," "developmentally disabled," "defective" and "retarded" have been used to describe this population(Tymchuk, 1990). Although some of these are historical terms and that have been used in a variety of ways in various cultures, a wide range of labels tends to confound attempts to describe those that are of below average intelligence. "Such inconsistency does little to further our understanding and those who write about this population must adhere precisely to an agreed upon definition" (Tymchuk, 1990, p. 22). In truth, these terms do not tell us anything about what has caused the disability or what potential the individual has, rather the terms divide humanity into two groups: the developmentally disabled and the non-developmentally disabled.

For the purposes of this study, the term "developmental disability" is defined as: "...individuals who are perceived by their families or communities as having a noticeable level of deficit from culture-specific norms of learning, behavior, intelligence and competence" (Miles, 1992, p.43). The indicators of a developmental disability include:

1. The disability is congenital (McCall, Hogarty, & Hurlburt, 1972; Tymchuk, 1990).

2. There are significant limitations in three or more adaptive skill areas: receptive and/or expressive language, learning ability, self-direction, capacity for independent living, functional academics, and/or personal health and safety (Feldman, 1986; McCall, Hogarty, & Hurlburt, 1972; Tymchuk, 1990).

3. The individual's IQ has been assessed by a standardized IQ test (WAIS-R) to be lower than 71 (British Columbia's Ministry for Children and Families, Memorandum, 1999).

Perhaps because there is a lingering cultural perception that child rearing is the primary responsibility of women, the term "parenting" generally refers to "mothering" in the literature. In addition, most studies recruit mothers as participants (Burt, Code & Dorney, 1993; Feldman, 1986; Budd & Greenspan, 1985; Ray, Rubenstein, & Russo, 1994; Traustadottir, 1996). While the term "parenting" does refer to both mothers and fathers, in this study I have chosen to focus on mothers as parents.

Intelligence as a criteria for program support

Who is or is not considered developmentally disabled hinges on arbitrary and professionally controlled definitions and classification procedures. "The construct of mental retardation exists in the minds of those who label other persons, and not those labeled; 'Developmental Disability' is a social construct and a cultural artifact" (Taylor, 1995, p.8). Although the literature provides many options for determining whether an individual has a developmental disability, I have found in my own practice that the decision by many government and community agencies to use intelligence tests alone to determine eligibility, omits the many other factors that define who we are as individuals. Intelligence tests do not measure one's personality traits, physical strength, dexterity, knowledge attained from life experiences, or ability to look after children. They are not predictors of social functioning; rather they are predictors of the potential for learning in an academic setting (McCall, Hogarty & Hurlburt, 1972). Although IQ has by no means been accepted as an accurate indicator of intellectual potential, in the absence of any other objective standard measuring techniques, "...it has been widely adopted by those offering services for children and adults with perceived learning difficulties" (Campion, 1995, p. 152).

Community Living Services (CLS) is a division of British Columbia's Ministry for Children and Families and provides specialized housing, parenting and/or employment programs to individuals with developmental disabilities. To receive these kinds of services, CLS requires that an individual have a psychological assessment indicating an IQ of 70 or less. It was my experience in the mid to late 1990's, that the 70 IQ criteria required for services was flexible if the individual (and/or advocate) could demonstrate a need for support to the Ministry's resource worker. As a reflection of current economic times however, the strict adherence to the 70 IQ criteria for service eligibility has meant that parents identified previously as in need of parenting skills training are now no longer eligible. This stricter criteria has seen the creation of a group of "de-labeled" parents who are no longer eligible for specialized programs, even though they continue to require the same support and training they received until recently.

Inconclusive numbers

Accurate estimates of parents with developmental disabilities are also difficult to ascertain because many parents with mild developmental disabilities live independent lives and receive little or no official help, and as a result, are not identified as having a disability. Those who have been identified often receive services from numerous agencies using a wide variety of disability definitions as discussed earlier in this chapter (Bakely, 1986; Ray, Rubenstein & Russo, 1994; Tymchuk, 1990).

Shifting Attitudes?

Much of the literature lumps all disabilities under one label as if the experiences of a woman with spina bifida and those of a man with a learning disability, are one and the same (Traustadottir, 1996; Walker, 1989). Although some gains have been made in how individuals with developmental disabilities are perceived and supported, these individuals are often seen as collectively incapable of giving informed consent, legal authority, personal opinions or adequate childcare (Budd & Greenspan, 1988; Schilling, Schinke, Blythe & Robh, 1982; Vogel, 1987; Whitman & Accardo, 1990).

On several occasions my involvement with a family as a PSW (Parent Support Worker) has been the result of a complaint filed to the Ministry for Children and Families by a healthcare professional who was concerned for a child(s)' welfare. While this is an important and necessary role, it is concerning to me when the complaints are based solely on the fact that the mother or father has a developmental disability. Such stereotyping occurs in many systems within the larger culture, including universities within which research on individuals with developmental disabilities occurs.

It is the obligation of members of an ethical review board in an academic setting to ensure that potential study participants are not coerced and that they have the capacity to give informed consent. Not knowing the participants and their capacity, they rely on the ethical guidelines of the university. The Ethics Review Committee on Research and Other Activities Involving Human Subjects was at first unable to approve the research methods used in this study, because the population of interest was people with developmental disabilities.

> There is a tension between your characterization of the potential participants as 'cognitively (developmentally) disabled', on the one hand, and your claim that they can provide consent on their own behalf. How might the disability mediate their ability to make an informed consent? What are the assurances you can provide to the Committee that the individuals are capable of making the decision to participate in your study? (Ethical Review Committee, 1999)

My response was as follows:

> The individuals with developmental disabilities, whom I intend to focus my study on, make daily life decisions not only for themselves but on their children's behalf as well. These parents live in the community independently without any kinds of supervision or controls placed upon them. They pay bills, sign rental agreements and cell phone contracts, hold checking accounts, go on holidays, sign consent forms for their children's school trips and activities, and make important decisions around medical procedures for themselves and their children. Even though these parents

> have developmental disabilities, it does not mean that they cannot make functional decisions; the label of a developmental disability is not equivalent to a global incompetency.

However obvious this may seem to those who know, work and/or live with individuals with developmental disabilities, it also raises the important question of *who* should speak out for people labeled developmentally disabled. Should students and faculty, journalists, or members of other groups who have faced prejudice and discrimination, presume to understand and articulate the abilities and experiences of parents and family members with developmental disabilities? Taylor (1995) asserts that while outsider observations are important, so too are the perspectives and experiences of people labeled developmentally disabled:

> These perspectives must provide a starting point for all research and inquiries in the study of developmental disabilities. Consistent with a Disability Studies perspective, studies must focus on how people tagged as developmentally disabled view and experience their worlds (p. 6).

Obvious to the reader at this point is my bias that a developmental disability does not always point to an inadequacy in parenting. Managing this bias while being open to a different perspective, is one of the challenges within a study of this type. Therefore, I have endeavored to remain open to the possibility that the stereotypes are accurate as I listened to the participants in my study.

Purpose of the Study

Defining the purposes of an inquiry can be misleading, for it leads some to think that inquiry is of value for what it results in; the external end point.

> ...Inquiry is simply good in its own right as an expression and actualization of human capability, and the development of the capacity to inquire-into our purposes and values, into our individual and collective behavior, into the life on our planet-is to be celebrated and encouraged in it's own right (Reason, 1996, p.18).

Although Reason's framing of purpose appealed to me in many ways, including my status as a novice researcher who was confronted with the daunting task of constructing a thesis, I was also aware that a clearly stated purpose met my need for concreteness. Therefore, the purpose of this study was to situate the experiences of mothers with developmental disabilities within the larger culture while exploring and describing the culture of parenting from the perspectives of parents with developmental disabilities. My question was: *"How do mothers with developmental disabilities make sense of their parenting roles?"* Specifically, I wanted to know:

1. What do mothers with developmental disabilities identify as key issues in their role as caretakers?

2. Are the participant's experiences and understanding of their parenting roles, ontologically based?

With decisions concerning child removal often based on a judgement about the ability of the parent to care for the child, it is important to note that this report is not about what defines a "good" parent. It is about two mothers with developmental disabilities and their parenting-related experiences—both the good and the bad aspects. By contributing to a limited literature base that is currently comprised of outsider perspectives, information from this study will contribute to other ways in which to understand and work with these parents; ways that do not pathologize them based on their developmental disability. Developing a better understanding of the ways in which mothers with developmental disabilities experience mothering is of benefit for all involved in these families lives. With this understanding, the various family support professionals can begin to frame affiliation relationships in ways that are based less on the dominant culture's values and beliefs about the concept of "family"-- and more on the specific needs of the parent in front of us. Since mothers with developmental disabilities are not always able to communicate their feelings and needs in a manner that everyone can understand, it was my intention to examine the participant's perspectives of their parenting experiences. The opportunity to improve upon my practice skills and knowledge made this thesis topic especially appealing to me.

Summary

Since our culture and society do not typically believe that women with developmental disabilities are capable of parenting based on certain cultural beliefs, ethnography is an appropriate methodology. It allows me to consider the cultural factors embedded in the participant's stories. Since any discussion of issues relevant to individuals with developmental disabilities must begin by examining the events of the past, Chapter Two describes the historical treatment of individuals with developmental disabilities. Literature on the topic of families headed by parents with developmental disabilities, which typically focuses on parental inadequacies, is reviewed to examine the factors that influence the parenting practices of developmentally disabled mothers.

Chapter Three describes the ethnographic methodology and the specific methods used in this study. The essential core of all ethnography is concerned with the meanings of actions and events to participants. The chapter describes the methods of ethnographic data collection and analysis.

Chapter Four presents the participants' stories with an analysis of common themes that is contextualized within the mainstream culture that the women exist in. While there are differences that exist between the women, there are common issues as well.

Chapter Five includes an analysis of the key issues of the participants as they compare to the current literature related to those issues. The implications of these findings for families headed by parents with developmental disabilities and those that support them are also examined.

Chapter Two: The Literature Review

Looking Back

The life experiences of people who are developmentally disabled have been dominated by non-inclusive, devaluing, exclusionary, discriminatory and abusive practices including "...forced segregation, government sanctioned abuse and dehumanization, public humiliation, involuntary sterilization, denial of fundamental rights, and even euthanasia" (Taylor, 1995, p. 7). In essence, they were treated as lesser individuals who were not permitted to participate in society and upon whom attempts were made to eradicate them as individuals and as a group (Feldman, 1986).

In the late 19th century, the theory of eugenics was advanced by Francis Galton. This theory held that by selective breeding, the quality of human beings could be improved and that social ills could be eradicated (McLaren, 1990). A diverse group consisting of cattle breeders, leaders of the women's movement and social scientists, first advocated for eugenic policies. Prominent in this group were Canadian leaders including Emily Murphy, a women's rights activist and the first female magistrate in the British Empire; Charlotte Whitton, a child welfare advocate and social work pioneer; and Clarence Hincks, psychiatrist and founder of the Canadian Mental Health Association (Ford, 1997). It is interesting to note that these individuals (considered progressives), were all from "…key professions which might have been expected to defend or at least be concerned about the rights of people with disabilities" (Ford, 1997, p.10), but who chose to portray individuals with developmental disabilities as menaces to society, while continuing to actively promote sterilization laws.

In both the United States and Canada, policies and legislation were adopted with the intention of thwarting the reproduction of individuals with developmental disabilities. In the United States, the landmark case of Buck vs. Bell called for and approved such legislation and many states did enact sterilization acts. Supreme Justice Oliver Holme likened the sterilization procedure to a public vaccination and declared, "... in order to prevent our being swamped with incompetents, it is better for all the world if society can prevent those who are manifestly unfit from continuing their kind" (Rioux, 1987, p. 65). In Canada, two provinces enacted legislation authorizing the sterilization of the so-called "feeble-minded". Alberta adopted this legislation in 1928, with British Columbia following suit in 1933, with both Acts remaining on the books until 1971. In Alberta, approximately 4,725 individuals with developmental disabilities were proposed for sterilization. Of the 2,822 cases approved by the eugenics boards, 64% were women. In fact, no group of women with disabilities has ever been as severely discriminated against in terms of their reproductive rights, as have women with developmental disabilities (Traustadottir, 1996).

The Canadian legislation authorized non-therapeutic sterilization on the same grounds as the U.S. but it was not until a number of developments occurred that the constitutionality of sterilizations of individuals with developmental disabilities was undermined. One development was the realization that only a small percentage of developmental disabilities are a result of abnormal genes or chromosomes. Another was the US Supreme court's recognition that producing offspring is a basic human right. But perhaps most significant was the end of the second world war and the vilification of what came to be seen as Nazi policies. Eugenics, sterilization and the "master race" philosophy came to be attributed to the Nazis – even though Canada, the US and others had similar policies. Sterilizations continued to occur, but eugenics was no longer promoted very loudly or publicly because of the Nazi excesses and the creation of the myth that the Nazis were responsible for the idea of a master race. Similarly, Canada's Charter of Rights and Freedoms, Section 7, states that: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice" (Gilhool and Gran, 1985, p. 178).

In 1982, the inclusion of mental and physical disabilities as prohibited grounds of discrimination under the law in Section 15 of the Canadian Charter of Rights and Freedoms was seen by many as the "crowning achievement" in these legislative developments (Hayman, 1990; Haavik, & Minninger, 1981). Instrumental in these proceedings were a number of advocacy groups, including the Consumer Advisory Commission and the Canadian Association for Community Living, guided by the conviction that nonconsensual sterilization was clearly in violation of one's human rights, regardless of mental capacity.

However, it was not until 1986 that the case of "Eve" (a pseudonym given to a young developmentally disabled woman by the trial judge), forever altered the legislation in this area. Eve's mother, ("Mrs. E.") first initiated the landmark court proceedings when she applied to the Prince Edward Island courts for full guardianship of her adult daughter so that she could authorize Eve's sexual sterilization, specifically a hysterectomy. Following eight years; three subsequent appeals; the dogged efforts of the Consumer Advisory Committee, (a group of self-advocates for persons with developmental disabilities); the support of their lawyer, David Vickers, and the Canadian Association for the Mentally Retarded (now the Canadian Association for Community Living) the Supreme Court of Canada ruled involuntary, non-therapeutic sterilization, (i.e., third party consent) as unlawful (Rioux, 1987). In his 69-page judgement, Mr. Justice La Forest states:

> The grave intrusion on a person's rights and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never safely be determined that such a procedure is for the benefit of that person. (Rioux, p. 55, 1987)

Although the issue of whether to prevent the occurrence of families headed by parents with developmental disabilities briefly left the political spotlight after the case of Eve, the child welfare system continued to be invested with the mandate to decide whether any parent, including those with developmental disabilities, was capable of looking after a child. It may also be instructive to note that the increased segregation and institutionalization of developmentally disabled individuals, the eugenics period and the emergence of the Child Protection movement, were all occurring around the same period of time.

> ...it could be argued that this was in fact a single movement, in which confinement and sexual sterilization of people with disabilities were presented by the new 'social scientists' as necessary for the improvement indeed, for the salvation of 'the race'. (Ford, 1997, p.10)

The Child Protection movement eventually came to be seen as having the expertise to judge these parents' ability despite the fact that schools of social work – the preferred training ground for child protection workers in most jurisdictions – provide little or no background information about disability or the assessment of the abilities of people with disabilities. It continues to be common practice for social service agencies to seek judicial severance of a developmentally disabled parent's rights before or soon after the child is born on the grounds that the parent would "inevitably" neglect her/his child (Llewellyn, McConnell, Cant & Westbrook, 1999; Stanford Law Review, 1979; Tymchuk, 1990).

In British Columbia, numerous government reports and investigations recommended changes to the child welfare system, which have included integration of services to children between the different ministries as well as integration of services to adults with developmental disabilities (Ombudsman Report, 1990). The Gove Report (1995) was yet another attempt to rectify the inadequacies of British Columbia's Child and Family welfare system. Judge Gove first sought to understand the child welfare situation in British Columbia's in response to five year old Matthew's Vaudreuil's death in 1992, after severe and ongoing neglect and abuse by his developmentally disabled mother, Verna. A key concern was that Matthew's death occurred despite "interdisciplinary" government and community agency involvement with the Vaudreuil family. Nevertheless, Gove failed to conduct an analysis of approaches, (ie: for parents with disabilities, etc.) and disregarded the secretariat's recommendation for an integrated model in favour of the establishment of a single government authority who would take over the staffing, budgets and resources of the 63 programs housed in nine ministries.

Although many of the investigations in British Columbia's Child Welfare history were fruitless in their initial recommendations, they were important processes nonetheless. The reports help us to remember the "Matthew's" and "Verna's" who have been let down by the system, while serving as documented history--'paper trails'--of those opportunities lost in the painstaking and long process of government, community and individual understanding and reform. It is hoped that by understanding what happened to Matthew and his mother, we can better address the needs of all families in crisis and, for the purposes of this report, particularly the needs of families headed by parents with developmental disabilities.

The Social Construction of Gender and Disabilities

Gender, disability and denial of citizenship rights come together most starkly in the area of sexuality, reproductive and marriage rights. Since Athenian times, people with disabilities, slaves, and poverty stricken families have been either “excluded by law from citizenship status, physically prevented from taking any active role in supposed democratic societies, or indirectly constrained by discriminatory and oppressive institutions. ...The concept of a disabled citizen, is a contradiction in terms” (Meekosha and Dowse, 1997, p. 70).

Women with disabilities have long been perceived as dangerously fertile and potential breeders of freaks. Rarely have they been acknowledged as having sexual desires or as objects of desire (Asch & Fine, 1988; Traustadottir, 1996). Many contemporary writers assert that race, ethnicity, class and gender identity are the distinguishing factors used to measure the value of one’s social standing within today’s diverse societies (Asch & Fine, 1988; Hooyman & Goyea, 1995; Meekosha & Dowse, 1997).

It is important to note at this juncture, that the emphasis in this report on feminist perspectives does not negate the discrimination and challenges that fathers with developmental disabilities face. However, the issues that women experience are more complex and different than men's experiences (i.e. women are the ones who actually bear the children and who historically have the responsibility for raising them). These differences may uniquely affect the parenting practices of women with developmental disabilities. Weinberg's finding that men have better self-concepts than women because the male sex role is more valued than the female sex role in North America, is not a new concept. However, the notion that disabled men have a better self-image than disabled women, might be (Cited in Asch & Fine, 1988). Weinberg asserts that if disabled men adopt the male characteristics of assertiveness, independence and pro-activity, they can get an "edge" on the disability that is unavailable to women. "By refining their adeptness at the "male" role, they can escape some restrictions of the "disability" role" (Asch & Fine, 1988, p. 24).

Social roles in the dominant culture are for the most part, situationally determined and can change over time. Yet women's traditional roles as nurturers, mothers, wives, homemakers and lovers are still not seen as appropriate for women who have disabilities, both physical and developmental. Unlike previous societal taboos, (i.e., teenage pregnancy, common-law marriages, etc), the concept of parenting with a disability does not seem to reconstruct itself with the changing times. Craft and Craft illustrate the hypocrisy by defining "the 'normal sociosexual' model as finding a mate, marrying and having children" (1983, p. 187). When a woman with a developmental disability becomes pregnant, the event is not usually met with pleasure and congratulations, but is viewed as a horrifying event with the implication that someone is to blame; either the woman herself or someone else who has "taken advantage" of her. "Persons with developmental disabilities are like 'eternal children'" (Havik & Menninger, 1981, p. 89). "They are pervasively incompetent and are more different from the rest of us than they are like us" (Espe-Sherwindt & Crable, 1993, p. 156).

Delimiting stereotypes around marriage and children make developmentally disabled women not only part of a social category that is demeaned across situations and time; but a phenomenon manifested in textual forms. All forms of stereotyping have played major roles in the development of laws and regulations that have restricted or prohibited persons with developmental disabilities from marrying (Vogel, 1987). Contemporary feminists stress the importance of understanding disability not as an inherent tragedy, but as a social problem created by a lack of sensitivity and awareness to the experiences of women with disabilities— and to the physical, social, and psychological barriers that occur as a result of this insensitivity (Asch & Fine, 1988; Burt, S., Code, L. & Dorney, L., 1993; Traustadottir, 1996).

Although the idea of being "roleless" may sound liberating to some, Asch and Fine (1988) argue that to not have roles to aspire towards—or reject—can "...cultivate a psychological sense of invisibility" (p. 13). Disabled girls grow up feeling not just different but inferior and feelings of incompetence and low self-esteem are common characteristics of developmentally disabled mothers. A reluctance to liberate antiquated stereotypes may well be the single impediment to full citizenship by women with developmental disabilities (Espe-Sherwindt & Crable, 1993; Tymchuk, 1990).

The Social Construction of Parenting with a Developmental Disability

> In truth, our society is not adequately supportive of any parent. There is no real training for parenthood, so the reality comes as a surprise to most of

> us. Parenthood is the hardest job anyone will ever have; yet the disabled parent may be the only parent in the neighborhood toward whom the community directs its anxiety about the difficulties of the job. (Lemaistre, 1985, p. 285)

The notion of parenting is rooted in the fulfillment of a child's emotional, cognitive and physical needs (Tymchuk & Andron, 1992). Parenting involves skills and practices that guide individuals in their role as parents as they negotiate the stages and transitions of family life. Rutter (1983) suggests that parenting is a function of having: (a) The ability to respond and cater to the child's basic needs.(b) The ability to love and undertake relationships.(c) The ability to care, support and nurture other people. (d) The ability to communicate, through active listening, giving appropriate verbal and non-verbal messages (p. 80).

However, there are aspects to Rutter's definition that are of some concern. The excessive use of the abstract term "ability" assumes that there are universally agreed upon definitions of what constitutes parental ability. This not only ignores the fact that there is currently a wide range of definitions in the literature on what qualifies for "adequate parenting" but it also negates the realities of diversity and that different cultures view parenting roles based on a number of factors including: personal values and beliefs, religious convictions, childhood experiences and life experiences. Often, professionals discuss and write about mothers with developmental disabilities in terms of the problems they pose for the social welfare services that encounter them (Budd & Greenspan, 1985; Whitman & Accardo, 1990). "...While the prevalence of mentally retarded parents may not be large, the multiplicity of problems they present and the lack of research on assessment and training of parental competencies, make them extremely difficult and time-consuming cases" (Feldman, 1986, p. 777). Rarely do they write about the parenting experiences of these parents in a manner that illuminates their strengths, individuality and day to day parenting experiences that are often reflected in the dominant culture.

It is not an objective of this report to minimize the fact that many parents with developmental disabilities have tremendous difficulties providing adequate care for their children. However, it is important for readers to understand that there are conditions that facilitate "effective" or "good" parenting and that these conditions are not distinct to families headed by parents with developmental disabilities (Espe-Sherwindt & Crable, 1993; Tymchuk, 1990, Feldman, 1986). In fact, there is research that indicates "... mentally retarded parents can be caring and giving to their children to the point of utter selflessness" (Hayman, 1990, p.103). For over a decade, Tymchuk (1990, 1992), Tymchuk & Andron, (1992) and Feldman (1986) and Feldman & Walton-Allen (1997) have empirically demonstrated that many parents with developmental disabilities are competent and that most parents can improve their skills with training. Parental behavior and life circumstances and experiences, not the label of having a developmental disability, are the critical dimensions on which to evaluate capability for adequate childrearing (Campion, 1995; Feldman & Walton-Allen, 1997; Tymchuk & Andron, 1992).

It is important to emphasize that parenting in modern urban societies requires a higher level of social functioning than it did even as recently as ten years ago with the increased expectations of parental involvement in schools, increased interactions with various professionals, and increased knowledge required with regards to technology.

Such societies can be very disabling environments for those with low economic resources, low literacy and a lessor capacity to think in the abstract (Feldman & Walton-Allen, 1997). Of those parents who live in supportive environments that accommodate limited financial resources, illiteracy and a slower pace of learning, it appears that many do well.

Moving Beyond the Myths

> Parents with developmental disabilities are like all other adult learners: they learn [sic] best when they are respected, when their life experience is valued, when their own unique learning styles have been identified, and when their "need to know" drives what is being taught. But by far the most important factor that contributes to the success or failure of a parent with a developmental disability, is the attitude of those with whom they interact. (Espe-Scherwindt & Crable, 1993, p. 165)

Regardless of evolving and often conflicting definitions of what constitutes a developmental disability and/or adequate parenting, society's assumptions seem firmly embedded in the notion that limitations experienced by individuals with developmental disabilities are pervasive and all encompassing (Bakely, 1986). Proponents of the feminist perspective and Social Role Valorization (SRV) theory advocate the construction of people with disabilities as having the same human rights as people without disabilities, and are opposed to a mainstream that imports values that are based on dominant white, male, conservative ideologies. Diversity among dominant cultures is key but a reluctance to liberate antiquated stereotypes may well be the single impediment to full citizenship by women with developmental disabilities (Asch & Fine, 1988; Espe-Sherwindt & Crable, 1993; Kendrick, 1994; Tymchuk, 1990; Wolfensberger, 1972).

Evolving from the “Normalization Principle,” SRV is a theory that has adopted many of the same concepts as its predecessor (Kendrick, 1994b; Wolfensberger, 1972), Even the term "Social Role Valorization" illustrates the inherent difficulties that have been associated with the negative connotations of the term "Normalization Principle". SRV also characterizes the explicit goal of SRV as being one that facilitates the creation, support and defense of valued social roles for people who are at risk of social devaluation.

Kendrick (1994) identifies the following 12 statements as key tenets of the SRV theory:

1. SRV identifies social devaluation as a critical human experience and tendency.

2. SRV raises consciousness and concern about the fate of socially devalued persons.

3. SRV invites and provides a way for individuals to take a stand against social devaluation.

4. SRV specifically enables socially valued persons to ally themselves with socially devalued persons.

5. SRV is largely consonant with the deepest and most enduring religious and civic values of the western world.

6. SRV recognizes and seeks the primacy of profound values change.

7. SRV illuminates the complicity of societal structures, agencies and systems in the transaction of social devaluation.

8. SRV proposes positive strategies of program and community change.

9. The depiction of social reality by SRV is substantially consistent with established social science, research and empiricism.

10. SRV acts as a safeguard against and inhibitor of further or more extreme forms of social devaluations.

11. SRV embraces a highly realistic sense of human nature.

12. SRV presents a response to the human degradation of social devaluation that is life-giving if combined with affirmative positive value choices (Kendrick, 1994, p. 15-18).

Wolfensberger (1972) and Kendrick both suggest that all other key tenets and objectives of the SRV are moot points if one's social role is not valued by society because if this were so, desirable things would be accorded to that person almost automatically, or at least within the resources and norms of his/her society. For the purposes of this paper, Kendrick's 2nd, 8th and 11th tenets are what this study has tried to emulate and these are considered in the following sections.

The Need to Hear their Voices

There are only scattered accounts of motherhood as experienced by women with disabilities, most of which have been written by women who have physical disabilities (Traustadottir, 1996). It appears that the bulk of the literature on parenting with a developmental disability relies on the perspectives of professionals while the voices of the developmentally disabled parent are silent (Asch & Fine, 1988; Meekosha & Dowse, 1997; Traustadottir, 1996; Walsh, 1998). There are pitfalls in relying on any one perspective in the interpretation of a phenomena or culture that are best explicated by author Jane Flax:

> Postmodern discourses are all “deconstructive” in that they seek to distance us from and make us skeptical about beliefs concerning truth, knowledge, power, the self, and language that are often taken for granted within and serve as legitimization to Western culture. (1987, p. 627)

With the power to label is the risk that those in dominant positions in society are given the capacity to categorize and discuss the experiences of those who have less power. This bias distorts what we know about women in families and about women generally. Most distorting perhaps, are the images held by society of the family as caring, loving, “the bedrock of society”, a “haven in a heartless world”, where women “build nests” for the happiness of men, children, and themselves, and so on. Some families may be all this, but familialism tends to deny that family can have negative aspects, too.

Any constructive change strategy must grapple with the problem of society’s perception of people with disabilities because it presumes that they cannot, and/or are unwilling to contribute when in reality, people with disabilities can make contributions as varied as anyone else’s. Conspicuously absent in the forums held by Judge Gove in 1994 were the voices of parents who have developmental disabilities. “While paternalistic approaches in the field may bring about improvement, change is limited if it does not consider the will, insights, and aspirations of people with disabilities” (Kendrick, 1994, p. 369).

My belief in the power of voice was reaffirmed in 1991 after witnessing the impact of a “self-advocate” (person with a developmental disability) who stood and spoke at a community agency's board meeting. An unusually high number of members attended this meeting to vote on the long anticipated proposal to change the associations' name from "The Capital Region Association for the Mentally Handicapped," to the "Victoria Association for Community Living." Many of the senior parents, some who had been responsible for the creation of the agency in the mid-1950's, told the packed hall that they were against a name change because they believed it would confuse other community and government agencies about the 'type' of people served by the Association. Other VACL members spoke to the issue of negative labeling against the very people the association provided services to. However, it was the last speaker of the night who captured everyone's attention when he stood up in front of the packed audience and articulated his feelings and thoughts about the label "mentally handicapped" from his perspective as an individual with a developmental disability. He explained that being identified as mentally handicapped bothered him because it paralleled too closely a term he particularly disliked, "mentally retarded", a term that didn't make him feel very good about himself. The vote, taken immediately after he sat down passed the motion overwhelmingly in favour of the name change.

Although individuals with developmental disabilities do not always understand all aspects of the many processes in our society, it does not mean that they cannot express and describe their experiences well enough to initiate understanding by the non-disabled dominant culture. Certainly, in contrast to people with physical disabilities, such as deafness, blindness, or mobility impairments, those labeled developmentally disabled cannot always communicate their views as effectively as the man at the VACL board meeting. However, if the starting point for inquiries into the disability experience is the point of view of disabled persons themselves, then the perspectives of people defined as developmentally disabled must be taken seriously. It is a problem to be solved, rather than grounds for dismissing these individuals' points of view and it is society's responsibility to discover how we can begin to understand their subjective experience.

One of the aims of ethnographic research is to give voice to stories not heard in the traditional narrative, while using a respectful and collaborative manner. The value of this approach is that it allows for reflective discussion and examination of the diversity of meanings and themes and the cultural factors within which the participants' stories are embedded (Denzin, 1997; Shepard, 1999; Spradley, 1979).

Chapter Three: Methodology

I chose qualitative research methodology, specifically ethnography, for this study so that I could explore the parenting related issues of mothers with developmental disabilities in a real life context. Qualitative methods encourage exploration and are best used when the researcher's goal is to display, describe and understand a phenomenon where present theory is not adequate or does not exist (Creswell, 1998). Ethnography suited my research purpose, (to explore the experiences of mothers with developmental disabilities in regards to their parenting roles), because in addition to etic perceptions, it also attempts to capture emic perceptions of meanings and events within specific contexts (Spradley, 1972).

Evolution of my Ethnographic Tendencies

Children in every society act like ethnographers: "…they ask questions to discover what other people believe, what they mean by the words they use and which forms of behavior are appropriate—and they are able to report their findings back to their friends" (Spradley & McCurdy, 1972, p. 13).

My fascination with the stories that people tell and the various perspectives that come with them likely originate from a childhood spent on the West Coast of Vancouver Island at the far end of Long Beach, where my father and I lived in a little A-Frame house. In some respects my childhood was representative of many children who live in rural communities, yet extraordinary enough to offer up experiences that have influenced how I currently make sense of this ethnographic research project.

Our A-Frame was situated just above the logs overlooking a coastline where westerly storms often blew and where with each spring came an influx of people that doubled the population in the surrounding area. Their wide variety of behaviors, physical appearances, languages and lifestyles endlessly captivated me. There were "beachcombers," "hippies/shrubs," "teens," "gorbies" (tourists), "locals," "natives," "summer workers," "fishermen" and "loggers," just to name a few. My enculturation with the many groups who lived on the West Coast of Vancouver Island occurred during the 1960's and 70's, from the age of six until I moved to Victoria when I was 15 years old. Attempting to understand the differing perspectives and the cultures represented by them, I observed the various groups in their use of language ("lingo"), their daily activities, and the foods that they ate—all from the standpoint of an adolescent girl.

There were many summers that I rode my bike to nearby "Wreck Bay," spending hours with the resident hippies in and around their driftwood homes, chatting with the old gold miner who lived on the beach next to the stream where he mined for tiny gold pieces, or with a school teacher and her family whose cabin sat on the hill overlooking the bay. There were also beachcombers whom I loved to watch walking the tide lines in their full issue yellow rain gear. Their willingness to teach me the art of beachcombing enabled me to decipher which beaches would consistently yield uncrushed seashells by observing the tides, the shapes of the pebbles, as well as the shape of the beach itself. I also learned that "treasures" were often in the eye of the beholder.

On some days at Long Beach, there were quick trips into the nearby town with my father to pick up supplies and, like most small towns, there was a wide diversity of locals who lived there. Fishermen (and fisherwomen) were a group easily discernible—even when not at work. Tell tale signs included the ever present knee-high rubber boots, a distinct odour, and the incessant talk about "Smiley's," "Dogs" and "Humpies" (AKA fish). Other groups in the area with distinct cultural portraits included the Nuu-Chah-Nulth Band, a local First Nation's community. The first five years of my elementary education were spent in a two-room trailer that provided education for both First Nation and non-First Nation children, the former came from the Esowista reserve, situated less than 50 yards from our school. My father had a casual friendship with a local tribal chief and his wife, yet we knew little of the cultural practices of First Nation's people. Their history with people of European background made them wary and they guarded very carefully the practices of their culture.

As with many of us who do not view life from the perspective of a minority culture, I accepted this dissidence without much consideration of the antecedents. Although not particularly helpful to First Nations communities and the issues they continue to be faced with, it was these diverse, early experiences that have influenced my interest in understanding the lives of marginalized groups who share the same living environment as the dominant culture. Inadvertently, these amateur explorations of the cultures of my community, introduced me to the basic tenets of ethnographic research.

Biases and Assumptions

I began working with people who have developmental disabilities in the late 1970s when governments and communities were still attempting to construct institutions as humane and economical solutions to "housing the mentally retarded." My very first year of working in this field was spent in one of these institutions hired as a "health care worker". Early in my nine months spent in this work environment, it became increasingly apparent that just as in many organizations, the residents were situated at the bottom of the institutional hierarchy, evidenced by their lack of choice, freedom or voice. Within four months of being hired and fresh out of college, two co-workers and myself became involved in a controversial incident that continues to influence my beliefs and values with regards to the rights of individuals with developmental disabilities.

In this institution lived a ten-year-old boy named "Peter," who, as an extremely self-abusive child with autism, gave himself a subdural hematoma, (bleeding in the space between the brain and skull). After more than two weeks of vomiting, not eating, and an oozing head wound, Peter had his first grand mal seizure and became paralyzed on the left side of his body. Even though this little boy lay motionless in his padded room for four days, the institution physicians and director chose not to admit him into a hospital. It was at this point that my coworkers and I decided to speak out to the local media, believing it to be incredibly arrogant for the institution to presume they could provide "adequate" care to a trauma patient. A subsequent investigation —conducted by doctors only—found that the institution had not been negligent and therefore could offer no recommendations for preventing similar situations in the future. Although the three of us were never identified as the "whistleblowers," I reconsidered my career choices and within months left that kind of work environment for a community agency. Since then, discussions that attempt to legitimize the notion that individuals with developmental disabilities do not merit the same human rights that non-disabled individuals are entitled to, disturb me greatly. Individuals with developmental disabilities do in fact, have the right to the same expertise in medical attention, and to make their own choices about issues such as where they want to live and work, or whether or not to have families. They also have the right to be represented in the research literature.

Creswell (1994) advises against doing research in one's "own backyard" because those too close to the "frontline" are subject to difficulties with objectivity. While the goal of objectivity in scientific knowledge is to be free of bias or prejudice, there are those who do not believe this is necessarily desirable and that the social scientist should be critical and espouse particular values (van Maanen, 1988). Postmodernists' assertions that scientific methods are only one way of telling a story about the social world among many other kinds of dialogues, suits my own reservations in making generalizations about mothers with developmental disabilities that do not take into account the context of each person's life experiences and circumstances.

In my role as researcher and through the use of inductive reasoning, I have attempted to examine the nature of this phenomenon, 'how mothers make sense of their parenting roles', from within the contexts of my axiological assumptions. While my life, educational and work experiences are important, the values I have accrued, as a result of my experiences, need to be bracketed and identified as "experiential knowing." Throughout the course of my research I attempted to remain aware of the epistemological factors, while ensuring my interpretations and connections to the literature were sufficiently interwoven with the participant's words (Creswell, 1997; Denzin, 1997; Shepard, 1999; Stuart, 1998).

Overview of ethnography

The essential core of ethnography is concerned with the meanings of actions and events to people—those that are personally, socially and culturally constructed through the use of narrative dialogue and stories and using a holistic contextualized approach (Spradley, 1979). The ethnographer assumes that although people share similar life experiences, how they interpret these experiences consists of unique, multiple, and often contradictory processes that "are situational, gendered, contextual, biographical, political, and historical" (Denzin, 1997, p. 47).

Ethnography is also an exploration of a social phenomenon, rather than an attempt to test a hypothesis about it. This perspective implies that the researcher must suspend preconceptions and engage in the world of the participants under study, valuing the researcher-participant relationship over a particular outcome (Fetterman, 1989; Spradley, 1979). The methodology includes a cyclical process of data collection and analysis that includes verbal descriptions and explanations of the individual perceptions of human acts or events, and is from an emic (participant) perspective as well as an etic (researcher) perspective. An ethnographic approach is a self-reflexive process where "...the field techniques and methods should hopefully reflect and represent the researcher's images, understandings, and interpretations of the world or phenomenon under analysis" (Denzin, 1989, p.130). The use of numbers and statistical analysis take a minor role, if any, emphasizing the view that the researcher must be willing to learn from the participants (Spradley, 1979).

"With the postmodern era have come new epistemologies, paradigms and discourses, all of which have resulted in more reflexivity and concern about the effects of the ethnographic endeavor" (Denzin, 1997, p. 41). Specifically, there has been a demand for ethnography to reflect various levels of interpretation and meaning and to avoid making claims to represent the absolute truth or reality of the experiences described.

Abstaining from making generalizations is especially pertinent with this population of people who have been stereotyped for far too long and who have not had much success (or practice) defending themselves.

In an effort to avoid some of the significant errors that Margaret Mead made in her study on the culture of young Samoan women (Meade, 1928), I have taken Denzin’s warning about representation seriously. Sixty years after the study's findings were first made public, it was discovered that Meade's young participants had exaggerated the realities of their sexual lives. As a result, inaccurate generalizations and stereotypes about this culture were made in countless textbooks and university lectures, despite subsequent studies that found Mead’s findings invalid. The damage done to this culture as a result of that study will never be fully known. Therefore, to generalize about parenting by families headed by parents with developmental disabilities, based on my interpretations of this study’s findings alone would be irresponsible.

Participants

Using purposeful sampling strategy, I asked a colleague who works with women who fit the participant criteria to identify prospective study participants. Two women were described to me by the colleague, she later met with the potential participants to review the study’s purposes and procedures using a script (Appendix A). In particular, the women were told that their decision not to participate had no bearing on any services that they might already have now, or in the future, from any of the agencies that they were involved with. Although both participants have had contact with the agency that I presently work for, I have not had any professional dealings with either of them.

Once the two participants had indicated an interest in the study, my colleague thoroughly explained the Letter of Consent (Appendix B). When she was satisfied that the information had been understood by the participants, as evidenced by their comments and responses to her subsequent questions, their names and phone numbers were forwarded to me. Participants in this study were not chosen for a perceived "ability" or "inability" to parent, but for their willingness to discuss their parenting experiences. Participants' provided written permission (Appendix C) to review their IQ assessments and other file information, so that I could use this in conjunction with the subjective accounts they provided to me. (The women's IQ's were assessed at 68 (Margaret) and 59 (Mary); two standard deviations below the norm.) Neither of the women had a history of mental health or child protection concerns.

"Margaret" is approximately 35 years of age and lives with her second husband, David. She is the mother of two children: a son who is nine years of age and a daughter who is 14. Margaret is involved in many aspects of her children's lives and values having a "healthy relationship" with her husband.

"Mary" is in her early 40s and has one son who is now 20. Mary and her son continue to live together and while her son enjoys an active life that includes sports, work and friends, Mary spends much of her time alone except for occasional contact with other family members.

Ethical Considerations

I obtained the approval of the Ethics Review Board and the University of Victoria. Soon after, the participants were given a thorough and careful review and assessment of their understanding of the consequences, (by both my colleague and myself), at which point both participants signed the informed consent form.

One of the dilemmas I struggled with in this study was additional ways in which to ensure the protection of the participant's privacy, anonymity and confidentiality. Before the study began, one of the participants expressed a concern that she would be identified by a particular story because she felt it was a unique situation. Therefore, in addition to the assurances outlined in the consent form, I showed the transcribed data to both participants so that they could see their pseudonyms for themselves, and changed a few characteristics about the participants that may have identified them more easily. Both participants reported that they were satisfied with the additional precautions.

Another dilemma involving confidentiality, occurred during an interview when one of the participant's talked about her experience of having an abortion procedure. Realizing too late that the tape had ended and that half of our discussion was not recorded, I asked if she would mind repeating the story. She declined, later explaining that she did not want to talk about it because it was too painful and she had not intended to bring it up. While I did not insist, as per our agreement, my dilemma was whether or not to write about the abortion based on my own recollection. I chose not to, focusing instead on what was interesting and relevant about the situation, which was her reluctance to engage in discussions that were uncomfortable for her.

Data Collection

Interviews with the participants commenced on November 10th, 1999 and were completed by April 10th, 2000. Participants determined the locations of the interviews to ensure comfort and privacy; Margaret chose my home and Mary chose hers. I had two interviews with Margaret and three with Mary, all 45 to 90 minutes in duration. In an attempt to discover new information, I used a tape recorder, took field notes, made personal observations, and reviewed the participant's file information, with their written permission (Kvale, 1996). (Appendix C)

Interviews took the form of "informal conversations" (Patton, 1980). I followed the model of the open-ended interview, which has a semi-structured format characterized by the interviewer introducing an issue and then following up on the subject's responses. Participants knew they had the option of not answering and were encouraged to discuss any concerns they had about the study with myself or a counselor who was available to them.

I believe my status as a childless woman worked in my favor for this study because both mothers—especially Margaret—seemed more willing to go into detail with me than perhaps they would have with someone who was already a parent and whom presumably, already knew these things. In varying degrees of detail and frequency, both women talked to me about their pregnancy and childbirth experiences as if they were explaining it to someone who had little or no idea of what went on at these times. My sense was that they were a little more tolerant with my questions--Margaret more so than Mary--than perhaps they would have been if they thought the interviewer knew the "right answer" and that they were being tested.

Questions included:

1. What is it that you love about being a mom? What is difficult about it?
2. In what ways has your life changed since you became a mother?
3. Has your disability affected your role as a mother?

4. What does the role of parenting mean to you?

The above questions were usually answered quickly so I would then follow-up with more specific ones, such as:

5. Tell me about your family's favorite way to celebrate.

6. What do you remember most about your pregnancy/labour/birth?

7. If you were to go away for a weekend and I were to take your place, what would I need to know most about looking after your children?

The latter questions tended to illicit larger quantities of data given their sequential, prompting nature. During our interviews there were times when the participants wanted to focus on a particular aspect of parenting, (i.e. when the children were toddlers), and often after I felt we had saturated the topic area. I was less directive with Mary in the direction that our conversations took given her reluctance and at times difficulty with articulating some of her parenting experiences. Margaret's willingness to talk about her self and her family, enabled me to redirect her to a different topic as soon as I felt one had been saturated. I reflected the participant's comments back to them, sought clarification, summarized statements and asked questions (Kvale, 1996).

Mary's responses to questions that she felt confident with, such as "How do you express affection to Mike?" were usually brief and disjointed, but often meaningful: "Well I got, he got love for me and I've got love for him, I've got lots—we've got a lot of love for each other. But with us, I think it's kind of hard to show it sometimes." More open, unstructured questions, or questions that Mary may have perceived as potentially judgmental, e.g.: "What kinds of games/routines/activities did you do with Mike when he was young?" typically elicited an "I don't remember" response or she would redirect the conversation to a topic she felt more confident about (e.g., "I make dinners like chili, and I put in chili peppers, mushrooms, green peppers ..."). As my interviews with Mary progressed, I became more attuned to her non-verbal responses— a body language that was particularly revealing. There were sighs, eye movements and a tendency to switch tracks by getting up for more coffee, food, and/or cigarettes at certain points in our conversation. It was my assumption that she exhibited these kinds of behaviors to signify that she was not interested in pursuing a topic any further. Many of Mary's verbal and non-verbal responses were similar to families I have worked with whose memory, problem-solving and articulation abilities are impaired. However, Margaret's tendency to discuss some of the details of her parenting role—in great detail—were also common.

Margaret tackled the questions during our interview in a much more eager and proficient manner. She was able to give detailed responses to most of my questions as long as they were not too "open" as is discussed in the following section. Margaret seemed to be able to remember and articulate the details of her pregnancies, her children's births and the details of her relationships with her extended families much easier than Mary. While this could be attributed to the higher IQ score, I also believe that Margaret's life experiences, the social and professional supports that she sought out (ie: the professional counselling and her close involvement with her husband, community and some family members), and her willingness to take risks, all contributed to Margaret's comfort level and willingness to talk about her parenting experiences in our interviews.

Spradley has identified the essence of unstructured interviewing as "...the establishment of a human-to-human relation with the respondent and the desire to understand rather than to explain" (1979, p. 113). I asked the participants what their parenting experience was like: “What does the role of parenting mean to you?” before the interviews began so that the participants had an opportunity to reflect. Both participants stated that they needed easier, “smaller” questions-- a response that is consistent in my work with families headed by parents with developmental disabilities. As detailed further on in this section, I found that the participants did not respond to open, unstructured questions as readily.

First interview

While open-ended questions do have the potential to produce informative insights, based on previous experience, I predicted that my participants would have problems with these kinds of questions and opted to prepare semi-structured questions to go along with the open ones. Indeed as it turns out, there were only brief responses to the open questions. (Mary said “What do you mean?” to the above question, while Margaret said “That’s too big a question!”) Therefore, my semi-structured questions that followed the open questions were much more specific: “What was it about when your children were small, that makes you remember it as your favorite, (least favorite) memory?”

The data was immediately transcribed after the first interview with each participant, so that I could guide the second interview in relation to our conversations from our first interview.

Second interview

At the start of the second interview, I asked mostly structured questions in an effort to understand more about the responses in the first interview. For example, “You talked about not feeling very comfortable when Dane would say hi to strangers in the mall when he was younger: (a) What did you worry would happen? and (b) How do you feel about the situation now?"

Third interview (with just Mary)

My third interview with Mary was much like my second as she was particularly tired during our previous interview and asked that we re-schedule after we had talked for approximately 35 minutes. In this final interview, I asked semi-structured and structured questions based on her responses to our first and second interviews.

I arranged follow-up meetings with both participants to clarify meanings. I met in person with both women. After these coffee meetings, I spoke with the participants over the phone on a few occasions to confirm specific comments or emotions about certain events. They were very helpful in our person-to-person meetings and in our phone conversations, saying things like, "yes, that's what I meant" or "No, that's not what I meant/said."

Analysis

Wolcott (1994) maintains that description, analysis and interpretation are the three main ingredients in qualitative research. Based on the data and a review of the larger literature, I examined the data for patterned regularities and explored their meaning, relevance and impact in the analysis. I then situated the stories within the broader contexts. I analyzed each participant as a separate ethnography (an N of one) using the following procedural steps:

1. Data from each of the five interviews was professionally transcribed. I had three copies made of each interview.

2. I began the analysis/interpretation process of the two ethnographies by listening to the taped interviews on three separate occasions, without reading the transcripts. In doing so, I first obtained an overall feel for them.

3. I completed two readings of each of the five interviews with minimal highlighting and without cutting out specific phrases and quotes. I then read for a third time, with more detailed highlighting and cutting out.

4. Of the three copies made of each interview, one copy was used to identify significant phrases and codes, the second was used to cut out specific quotations which were then pasted onto 5x7 cards, and the third copy was used to sort the data based on events or situations (e.g., pregnancy, childhood, family background, births, etc).

5. For coding, I used "meaning condensation" which entails an abridgement of the interviewees expressed meanings into shorter formulations of the same story, where for example, paragraphs were compressed into brief statements or phrases such as: "Mary's emphasis on food" (Kvale, 1996).

6. The first grouping of the codes resulted in approximately 12 categories per participant. I then collapsed these categories and organized thematically. I identified the following themes for Mary: "Once in a Blue Moon," "It's a Reading Problem," "We're Like any Other Family," and "Seven Layer Dip."

For Margaret, the themes included: "The Duke of Edinburgh Awards," "The Most Exciting Thing is the Birth of the Child" and "You Sort of Learn as You Go!"

7. Spradley (1979) asserts that discovering cultural themes requires the ethnographer to look carefully over the data collected and identify recurrent patterns. These patterns both tacit (those that are implied or unspoken), and explicit (those that are clear and definitive), constitute the culture. Patterned regularities gradually emerged, for example Mary's focus on food, which I called "Seven Layer Dip," emerged after I began to see the significance that food has played in the many facets of her life. The same was true for Margaret's theme "You learn as you go!" where her belief that learning occurs solely as a result of experiences, is particularly evident.

8. I wrote individual accounts to represent each participant's perceptions, descriptions and reflections of their thoughts and feelings in their role as a mother.

9. Because I have conducted two ethnographies in this study (an N of 1), comparisons were made throughout Chapter Four, (particularly in the summary of that same chapter), as they pertained to each other and in relation to the dominant culture.

10. In order to obtain other perspectives, I had my thesis reviewed by my supervisor and a peer.

I did not accomplish this process in a linear fashion. At times I found myself going backwards and forwards between steps 3 and 8, endeavoring to sift through the mounds of data by adding to and weeding out information that was pertinent to my research question. Wolcott (1994) suggests that data can be analyzed at three different levels using varying degrees of description, interpretation and analysis. In no particular order of importance, the three types of analysis are as follows:

1. Description provides the subjective views of the participants and those of myself.

2. Analysis, the quantitative side of qualitative research, examines the similarities and differences between us.

3. Interpretation provides the researcher with the opportunity to explain the differences drawing from the literature and personal knowledge.

I structured and organized the following chapter using participant and researcher order and focused on the participant's perceptions of mothering as the "key event" (Wolcott, 1994). I grounded my reflections of what I had observed by working to present the information in a manner that would capture the reader's interest.

Limitations of the study

A small sample of two participants creates a risk that findings from this report will be subject to generalizations about the culture of mothers with developmental disabilities and perhaps perpetuate the stereotypes these women continue to experience today. Maynard (1994) suggests that the potential danger in qualitative research is that when social life is reduced to the definitions of the participants, it becomes a purely "subjectivist" sociology which loses sight of social phenomena. While I agree that Maynards' concerns have some validity, ethnographic methods have moved away from stating that they represent all cultures (Wolcott, 1994) In this paper I have reported on my own reflections and observations and detailed the culturally embedded stories of the participant's experiences of mothering. Upon checking with the participants and determining that many of these observations have credibility, the reader must judge how credible the findings are in relation to their own experiences.

Credibility: Trustworthiness of the Study

Denzin's assertion that "...there is no way to stuff a real life person between the covers of a text" (1989, p.82) rings true for this writer. Certainly stories of one's life experiences—including my Westcoast childhood—are not "real life," but reconstructed representations of people's experience and subject to further and different undocumented reconstructions by the storyteller, and deconstruction by whoever reads or hears them (Wolcott, 1994). Therefore, the status of the literature as a "representation" of a common culture is inappropriate. Rather, I want to illuminate the culture(s) of the developmentally disabled parent while heeding readers not to seek a generalization of the findings, but to use them to sensitize themselves to the possibilities.

This study is not suggesting that mothers with developmental disabilities all have the same viewpoints, beliefs and knowledge about parenting and that these are different from the dominant culture. Rather, the research suggests that these parents are more similar than they are different.

Summary

Ethnography allows us to consider the cultural factors embedded in the participant's stories. It appears that our culture and society do not tend to believe that women (and men) with developmental disabilities are capable of parenting. Using interpretive ethnographic methods, this research describes the lives of stigmatized mothers with developmental disabilities. I examine how my participants construct their "selves" in relation to their parenting roles and practices by observing, describing and interpreting the participant's stories, behaviors and communication patterns (Denzin, 1997).

The following chapter presents each of the participants' stories with an analysis of the participant's parenting themes and a contextualization of those themes within the culture that the women exist in.

Chapter Four: Findings

In this study, I have sought to unravel the essence of the two participants' stories through observation, an analysis of the transcripts and file documentation, and by incorporating my own knowledge and experience as a Parent Support Worker. In the course of my interviews with these two women, it became apparent that the underlying issues in their parenting roles often reflected their concept of societal norms and cultural expectations. From their culturally situated experiences, emerged themes that pertained to various mothering roles including: child-parent interactions, single parenthood, relationships, poverty, materialism, literacy and isolation—all familiar issues to mothers everywhere.

The Cultural Context In Which The Participants' Stories Are Situated

Western values currently emphasize independence of family, literacy and self-sufficiency. For instance, Campion (1995) asserts that in some European countries, it is disrespectful to the family and cultural traditions if a child leaves the family home before marrying. Likewise in Pakistan, children who are unable to read (even after tutoring), make "polite conversation" with guests or "serve tea," are never considered developmentally disabled, just "stubborn." In disabled communities on the other hand, there are some beliefs and values that are quite distinct from non-disabled communities including a growing group of non-hearing individuals who are not interested in some of the customs of the hearing culture—especially the ability to hear. Currently, controversy surrounds the use of cochlear transplants –procedures seen as desirable to mainly hearing parents whose children are eligible for the operation, but as the likely demise of the deaf culture to non-hearing individuals (20/20 TV documentary, May 5, 2000).

In my researcher role and coming from a white, middle income family, I was made aware of some of my own assumptions around cultural "norms," as the participants frequently reminded me that their experiences were very different than mine. Mary caught me by surprise when I asked if her family's traditions had ever included going on holidays together. My insensitivity about what poor rural backgrounds entailed was glaringly evident when Mary uncharacteristically snapped "What do you mean?" "Well," I said, now regretting my question, "do you ever go on little holidays or things like that with each other?" "Are you joking?" she demanded, seemingly amazed at my ignorance. Then, just as quickly, she changed her tone to that of a patient parent and explained, "We didn't have the money. We just had enough money to support (the baby) and sometimes I had problems getting pampers and milk."

Just as the above example illustrates, there are "norms" embedded in the culture of poverty that may apply to how parents with developmental disabilities are constructed by society. Understanding this helps us to challenge the significance that dominant cultures typically place on assets and "high intelligence." The following two ethnographies are the result of a series of interviews that took place in November and December of 1999. In an effort to describe the day to day experiences of these women as mothers, I have focused on themes that appeared to be pivotal to each of the participant's parenting roles and avoided the temptation to go in directions that members of the larger culture might perceive to be more pertinent to the parenting experience.

Mary's World

"Mary" is an affable forty-three year old single mother of a twenty year old man, "Mike". She left her hometown in Eastern Canada to travel to her new home on Vancouver Island in 1986 when her mother provided the airfare so that Mary and Mike could be reunited with her. Other than a few friends in her old hometown, Mary has led an isolated life and has relied on her family for many kinds of support, especially since Mike's birth.

Mary and I first set eyes on each other when I drove up next to her while she sat in my colleague's car, puffing fiercely on a cigarette in anticipation of our coffee meeting in a non-smoking establishment. Throughout our first encounter, Mary seemed pleased to have interested listeners and, with a timbre that projected nicely throughout our section of the restaurant, she guided our conversations around topics that were relevant to her life including the financial struggles, her extended family's activities and her plans for the upcoming Christmas holidays.

When we finally broached the topic of my study, I explained that our discussions would be left primarily up to her, but that I would try to guide our conversations around her parenting experiences. "Nobody is going to make me say nothing I don't want to talk about, so don't worry about that," she said assertively, and to which in hindsight I probably laughed a little too encouragingly. Yet as our conversation progressed, I observed a woman who appeared to enjoy discussing the details of her every day life.

In our society, great importance is placed on image, particularly the one that is presented to the world. This often manifests itself in the places that we live, the activities we participate in and the ways in which we communicate. Mary mentioned on several occasions that she was bored, housebound, and that she did not always like having people over because her apartment was "... messy, crowded and the rugs are really bad." Nonetheless, and despite offers to hold the interviews elsewhere, Mary decided we should meet at her home because she felt more comfortable there.

Mary's apartment building is on a main thoroughfare close to the center of town, and as I drove up on the day of our first interview she was waiting on the balcony, calling down to direct me around to the side door of her apartment, explaining that she would come and open it for me. Smiling widely, with a comb stuck purposefully in the back of her hair, her first words as I walked up were: "Don't mind me, I'm not in a good mood 'cause I got my bills today."

Not entirely sure that I was ready to begin the interview quite yet, we walked up the back stairs of the apartment block while Mary elaborated on the adversities of having only one welfare cheque of $600 per month, compared to the $400 biweekly cheques she received as a dishwasher three years ago. She finds her monthly cheques a long time to wait and that she has too many bills to ever get ahead, given her $400 monthly rent payment.

Cloak of Competence

As we entered the apartment, I prepared myself for the chaotic environment that both she and Lee had forewarned me of. While Mary apologized repeatedly for the mess, I did a quick scan of her apartment only to determine that it was not nearly as bad as I had imagined, and in fact nothing like what she and Lee had described during our coffee meeting. In fact, Mary's apartment was clean, tidy and bright. Her living room was just large enough for a couch with side tables on each side, an armchair, and a nicely decorated stereo cabinet. The dining room consisted of a table with only a few items on top and a small kitchen off to the side. It had been scrubbed down, showing off bare countertops and sparkling appliances. Mary's corner apartment reflected an organized, tidy tenant.

Our second interview on the other hand, revealed an entirely different backdrop to our conversations. This was an apartment in complete chaos, essentially what I had anticipated for our first interview. There was a "Hide-A-Bed"—not so hidden anymore—open in the middle of the living room with clothes, dishes, candy wrappings and other miscellaneous items piled high on top. The side tables were moved from both ends of the couch and were now on either side of the armchair, significantly contributing to the reduced size of the "living" room area. In the dining room, the kitchen table was repositioned making it difficult to access the kitchen or the living room, depending on the direction of travel. The kitchen was devastated: the cupboard doors and drawers were open and papers were strewn everywhere. There was garbage piling over and onto the floor, and evidence of at least three meals on the stove, in the sink and on the countertops. Mary and I cleared away some space and continued with our second interview until Mary grew tired and asked if I could come back the following week.

As our third interview day approached, I found myself strangely anxious to discover—but unable to anticipate—what the state of her apartment would be this time around. Upon arrival, my roving eyes were drawn to a new couch now situated in front of the old one, making the latter one unusable. Mary said she was storing it for her older brother until he could find a new place. The stereo cabinet had been moved—although not to accommodate the new couch—and it now sat directly in front of the glass doors requiring us to squeeze around it to access the balcony. The kitchen was ravaged, much like it was during the second interview. Once again we cleared some space and began our third and final interview while sitting amidst the havoc.

It is a societal norm that stability and happiness are achieved by routinized lifestyles. It was apparent to me after the first interview that Mary had become more comfortable with my presence and was not as concerned about what I might think of her if the apartment was untidy. It was also apparent that the requirements of maintaining a tidy home were less about Mary having the skills, and more about the low priority she has given to this aspect of her life. It is my belief that Mary thought that by welcoming me into a clean tidy home on our first interview, she would make herself look more "competent."

It is difficult to imagine what it must have been like for her son to live in a home that was constantly changing physical form as well as degrees of cleanliness. While it is possible that given the fact that this was something he had grown up with, it might not have bothered him. However, it is telling that her son's room is what Mary often refers to as "Mike's own little apartment." Mary told me he spent most of his days there, coming out only occasionally to get something to eat, to use the bathroom, or to leave the apartment. Although Mary quite rightly pointed out that this situation was typical behavior for a young man getting ready to leave the family home, it seemed to me that a lot of separation had been created within the small space that these two individuals share. It truly was as though they lived in separate apartments.

Edgerton (1967) describes "the cloak of competence" as a way that individuals with developmental disabilities learn how to function within a society from which many had been removed through institutionalization. Participation in the dominant culture's mainstream activities requires people to know how to find and build relationships, look after their own health needs and livelihoods, and for some, to become parents. Many individuals with developmental disabilities acquire only partial skills in these areas and compensate by doing approximations of the desired behaviours.

Mary clearly has an awareness of what behaviors make her appear to be competent to the rest of the world. It also appears that Mary understands that society has developed a set of standards, and that judgements are made based on these standards. As I listened to Mary talk, it was apparent that she has had difficulty achieving what would be considered "the norm" in the execution of many life skills as defined by the dominant culture. This was evidenced by a general reluctance or inability to describe in detail, certain aspects of her parenting role such as behaviour management, play activities, Mike's school activities, or the implications of her disability. Also evident were difficulties with interpersonal relationships and communication, (i.e., reading and writing). Mary felt that she did not need professional support programs to help her with parenting related skills because she already knew how to parent and if she did happen to run into difficulties, her mother would help her.

Given Mary's isolation, it is possible that her willingness to engage in a research project was more to do with having someone visit than about examining the implications of parenting with a developmental disability, especially a disability she is uncomfortable talking about. I come to this conclusion because other than her comment in the coffee shop, ("Nobody is going to make me say anything I don't want to."), Mary did not indicate to me or my colleagues that she had any concerns about this particular aspect of the study during the recruitment phase or when the consent letter was being explained and read to her. I assumed a level of trust was required before either of us could feel comfortable talking about her disability and while I believe this was achieved to the degree that three meetings with a stranger can permit, Mary never really opened up about her disability in relation to her role as a mom. In fact, I believe that Mary has many life stories that she is wary about sharing based on a fear that her cloak would be lifted for all to see, ultimately exposing her to criticism and negative feedback.

Mary's description of her parenting experiences clustered around four themes: "June Cleaver Archetype: We're just like any other family," "Seven Layer Dip," "Once in a Blue Moon," and "A Reading Problem."

June Cleaver Archetype: We're Just Like Any Other Family.

Parents with developmental disabilities often talk about the fact that they lead normal lives: an image that seemed vitally important to Mary's self-perception. Her aspirations in life are simply to be recognized by the dominant culture as a good mother who loves her son and who like many single mothers, is frequently forced to deal with issues related to poverty. The existence of a psychological assessment that identifies Mary's IQ level at 59, her difficulties in maintaining a home and a budget, and problems articulating her parenting knowledge and skills, all suggest that there are additional challenges.

I asked Mary what she loved about being a mom and without hesitation she replied that she enjoyed it most when Mike was a toddler. "He couldn't talk back to me," she laughed. "And going for walks with him in the stroller you know, I did that quite a bit. And I liked that I could take him out with me shopping." "You sound like you were a proud mom," I said. "Oh yeah," Mary replied enthusiastically, "We're just like any other family, you know."

Mary struggles with the distaste that she and many parents with developmental disabilities have when required to label themselves as having a developmental disability. Campion (1995) asserts that this is hardly surprising in societies where intelligence is valued so highly. "The constant fear that 'everyone else understands what's going on except me' can result in parents not asking for help when their children do need it and may underlie many of their own children's learning difficulties" (p. 163). In my experience however, most of the parents I have worked with have been quite comfortable in discussing their disability, perhaps the result of my role as a parent support worker (PSW) and someone who is "used to" supporting people who have developmental disabilities. Mary on the other hand, has not known me in this role and some of the questions that related to her parenting knowledge may have seemed judgmental to her, particularly for someone who has had her parenting skills more closely scrutinized than perhaps her sister or brothers' were.

Polite conversations.

Just before our first interview started, Mary called out to Mike in his bedroom to come and introduce himself. A tall, handsome young man with confident eye contact, he walked up and shook my hand and began to engage in "polite conversation" with me. This is what Miles (1992) alluded to earlier as the cultural expectations of young family members in Pakistan. After some small talk about the weather and the "joys" of living in an apartment, Mike looked towards his mother with the timeless expression that pleaded to be released from his social obligations. With a nod of her head that revealed some disappointment, Mike retreated to his "apartment." In our few, brief meetings, Mike presented as a very typical young man: a little awkward, but who was going through the motions of "social niceties." He did not reveal the typical characteristics of someone with a mild developmental disability. (To be discussed further in the third theme: "A Reading Problem".)

Many societies believe that the archetype of the perfect family is the "June and Ward Cleaver" model. One of the behaviors our society engages in to maintain this myth, is that of keeping secrets. Mary appears to have bought into the belief that in good families, bad things —such as having a developmental disability—do not happen. It is a belief that seems to be quite consistent with many families, both disabled and non-disabled: if you do not talk about it, it did not happen.

Mike's origins.

When Mary was 24, she met a man whom she declines to name. Within a few months of their relationship, her doctor informed her that she was pregnant. Mary was surprised because she had been "taking precautions".

> I was on birth control pills, and I guess they say they're fifty-fifty. Fifty nothing. (laughs) They don't work. ... But I was twenty-four at the time so I was basically ready.

Discussions about Mike's birth father and his reaction to news of the pregnancy were brief, but enough to indicate what must have been a difficult time for Mary.

> Well I can't remember his name, I threw it out. ...When he found out I was pregnant he said 'it's not my child'. We argued, I said 'yes it is'. And I

> told him, we'll find out when I have the child. So, I had him, I took him to family court. He looked at him, because I had him walking in the hallway, up and down the hallway. ...He was only a few weeks old or something like that, or a month old. Then he (Mike's father) looked at him and he said 'he don't look like me'. And I said, 'yes he do', I said 'look at his forehead and look at yours'. So I said 'he's got your forehead and your nose', so he shut up then.

Perhaps due to such a negative reaction by the birth father, Mary chose not to tell her friends or family of the pregnancy, indicating only that "they all knew when I got bigger." Mary was reluctant to elaborate what her thoughts were in regards to her family member's and friend's news of her pregnancy, other than to say "...but when I had him, they was happy". It is apparent that these reactions to an unplanned pregnancy are not distinct to families of mother's with developmental disabilities.

Although Mary does not remember if anyone was with her at the hospital when Mike was born, as with most women, the memories of labor and childbirth are vivid.

> Unforgettable. I still laugh when I was in the hospital, because I was in real—I was in pain! And I was in that room; they put you in a room until you go in to labour. Well I told the nurse that I was in pain. So she said ok, she said, I'll give you a pill. And I swear to God as of today, she gave me a sleeping pill. I swear she did! By the time I ended up in the delivery room, the doctor told me to push. I said "push what?" I said, I want to go back to sleep. Those are the exact words I told him. I said, 'No, I want to go back to sleep.'

Mary mentioned that the nurses had "slipped" her a sleeping pill, on more than one occasion during our interviews. It was a comment that struck me as quite unusual given that labor pains are not typically described by women as an experience they want to sleep through— unless they have been heavily sedated. My attempts to get a sense of what her labour had been like before she was given the sleeping pills, (was she frightened, crying or yelling?), was difficult to ascertain because this was the only part of the birth experience that Mary said she could not remember.

Mike's birth, "… a natural one," was a collage of emotions, as it is for most mothers, especially when for the first few moments after he was born, there was no movement and he did not cry.

> So I asked the doctor right away, 'is something wrong with the baby?' And he said 'No'. So, at the time—I don't know if they still do it or not—you know how they hold the baby up? They spanked his bottom. Well as soon as I heard him crying, I cried.

Asked soon after the birth by the nurses if she would like to breastfeed, Mary was not at all keen about the idea, telling the nurses "No thanks, no. That's something I don't want to know nothing about." Unlike today's culture, women were not pressured to breastfeed twenty years ago, rather it was a time when breastfeeding in a restaurant or at a bus stop was not generally accepted. Mary's need to blend in, or to appear "normal," would have been more difficult with the added pressure of being required to know how to suckle a child. Therefore, Mary sought a different, but culturally acceptable option in which to feed and nurture her child, even though it was financially taxing.

> And I just went ahead and tried him on the bottle, and I said let's see if he gets sick from the formula. And if he don't get sick, then I'll continue that. And then a few months down the road, I started him on box milk. Canned milk. He didn't get sick off it, and it was cheaper. ... I had his crib right in the same room close to my bed, and sometimes when he was sleeping, I'd

> get up and make a couple of bottles. And then let them cool, and then put them in the fridge and I'd take one in the room with me... and set it on the night stand and then when he wakes up, it's already warm for him. And then I'd just feed him and change him and burp him, and put him back to bed. And then he'd go right to sleep.

It is society's "norm" as well as an indication of a good mom, when one can get her child to sleep through the night— and it is a good baby who responds. Based on her observations of other parents in the community, the images on TV and of her own family experiences, Mary has developed a mental picture of what Mike's bedtime routine should look like, and did not swerve too far from this ideal in any of our discussions about bedtime and nurturing activities when Mike was young. There were virtually no instances where Mary indicated that there were nights when it was tough to get her infant son to sleep or days when she had had enough, as is commonly heard in the dominant culture.

Seven Layer Dip

Seven Layer Dip refers to Mary's pattern of detailed responses about food and its relationship to her definition of family and the prosperity it represents. Certainly, there was a focus on food for Mary in almost all of our conversations. I learned that Mary's family does not often have turkey, yams, ham, and roasted potatoes but that they instead celebrate with chicken, chili and seven layer dip. While this is likely the result of few economic resources, what is pertinent to this theme is what food represents: family, celebration, prosperity, and "living the good life."

Just as with many individuals, relationships are vitally important to Mary. When there was not enough money for food during her childhood and adult life, it was a situation made more bearable as long as the family was together and had food to share. The frequent use of the term "potluck" communicates that one of the expectations in Mary's family is that everyone must pitch in what they can, when they can. Although Mary's mom has since returned to Newfoundland, as the matriarch of the family it is still her role to supervise family gatherings, even if this requires doing so from the other side of the country via the telephone. During the period of time that our interviews occurred, and in preparation for a birthday party and the upcoming Christmas holidays, Mary's mother arranged who would bring what, where the parties would be held, and who needed to pull their weight more.

> Like this Christmas, my sister is, I guess my mother talked her into having Christmas dinner down at her house, because these last few years I've been having it at my house. So we will all make up a couple of dishes and take them down there. My brother, he made a *seven-layer-dip*, check it! (Mary's fist thumped the table as she said the name of the dish). Oh it was so good! And they'd cook like chicken or one chicken and another dish with it, and another one cooks something else. Like last year, a couple of years ago, well last year and the year after, I made a great, about one or two pots of chili.

Unable to articulate how deeply family and food are intertwined, when asked if she missed her mom, Mary replied: "Oh yeah. And she cooked a lot too!" Just as with many other cultures, food has more purposes than just sustenance for Mary. The family meal provides a picture of a happy normal family with no worries in the world. While the type of food upon the table may indicate one's status in the world, (i.e. turkey and yams, versus chicken and seven layer dip), in Mary's family it was not about what was on the table, but what it represented. In addition to family, Mary often talks about her own parenting skills in terms of the food she provided for Mike throughout his childhood and adolescent years. As long as Mike had all the right stuff at his birthday party she was a good mom, but more importantly they were "just like any other family."

There is a myth often perpetuated by the dominant culture that individuals with developmental disabilities have little to offer. Food represents the giving of one's self, something that may be unattainable in other areas of Mary's life. Mary gives much of herself and this is symbolized by the offering of a bowl of seven-layer-dip.

> Well, sometimes when Mike was young, I'd throw a party for him, and whatever friends he had at the time, which he's got a lot now, but whatever friends I knew that he had, I told him that he could invite them and I'd have a party for him. Like cake and chips, cheezies, candy, ice cream and sometimes I'd cook hotdogs and hamburgers and have the hamburger buns, hotdog buns, ketchup, mustard, relish and whatever. I used to have a lot for him.

Seven layer dip, a food that overlays a variety of different food items into which one can dip into and pull out a combination of different tastes, provides a visual image of Mary's adaptations to certain aspects of her childhood and parenting experiences as a mother with a developmental disability. The many layers that parenting can take and how Mary dips into these various layers, contribute to our understanding of why Mary has chosen to keep many of the personal details of her life away from non-family members—including inquisitive researchers. It also tells us what aspects of Mary's life she can dip into as potential resources in her life.

A Reading Problem

Mary grew up in a far eastern Canadian town where she attended "special classes" for persons with developmental disabilities until she left school at the age of nineteen. Living with her mother and father until they divorced when she was fifteen, Mary has had little contact with her father ever since. Mary and her infant son moved in with her mother and stepfather for the first year or two of Mike's life.

Mary and Mike have both been assessed as having a mild mental handicap (WAIS-R) and both show strengths in visual memory. Mary's strengths in particular, lie in the areas of reconstruction, visual memory tasks and recognition of missing material on a visual display. She also has relative strength with number concepts including adding and subtracting sums in her head, but has problems organizing and expressing her thoughts and finding the right words. "Her reading abilities are at about a grade one to two level, although she has good number concepts and the ability to manage her household." Using the Stanford Binet Intelligence Scale, 4th edition, Mary's IQ was assessed at 59 (Psychological Assessment, 1990).

Mike was characterized in his assessment as being "quick, playful and impulsive, … a slow learner with learning disabilities and social adaptive behavioral deficits. This is combined with his mother's handicap and her history of being abused as a child" (psychological assessment, 1992). Mike was assessed using the same intelligence scale as his mother, but was found to have a somewhat higher IQ of 77 than his mother's 58 IQ.

As previously mentioned, the importance of appearing "normal"—both as a parent and as a member of the community—is a strong theme in both participant's lives, but particularly with regards to Mary. In our interviews it appeared that Mary would be more inclined to talk about her perceptions of "family" (i.e., food, celebrations, loyalty, etc), when she felt sure she wasn't being "tested" and was knowledgeable about a particular topic. (i.e., the ingredients to various meals, the names of streets she used to live on, and gossip about her neighbors.) Although it is understandable, Mary was reluctant to consider the implications of parenting within the context of a developmental disability, unless it was described as "a reading problem."

It was not until our second interview, when I began to present the topic of having a developmental disability in terms of her strengths and *my* weaknesses, that Mary became a little more willing to discuss her own developmental disability.

> **Kelly:** With my weaknesses including math and memory, (I expanded on these), ... and knowing that cooking is one of your strengths, what areas would you say are not your strengths?
>
> **Mary**: Clothes shopping is another strength I have, (laughs), but sometimes I forget about things, and then I end up remembering them. Like going grocery shopping... I ask people that work there, or who are shopping, to help me find things because I've got problems with reading, a reading problem. And they says sure, no problem. And they help me, and I thank them afterwards.

When Mary's mother moved to Victoria with her second husband in 1985, she recalls feeling very lost and alone until her mother sent airline tickets for Mary and Mike to join them one year later. Packed and ready to go within days, Mary was eager to leave her hometown in the anticipation of a more exciting and prosperous life.

> Well in a way I was happy to get out of Newfoundland because there's nuttin' down there. I mean a job was hard to get and all I ever did is stay

> home, like I do now, without a job. I wasn't working for quite awhile and living in my uncle's house, the basement part of the house.

It usually seemed difficult for Mary to acknowledge the help that her mother had given her before and after Mike's birth; except for one conversation:

> Well either my mother helped whenever she could or, or— basically my mother helped whenever she could. She did help me out quite a bit. So that was when I'd thank God that I had her around.

On a few occasions, Mary was willing to discuss Mike's development in relation to the mothering skills she had obtained by watching others. "At first I didn't know what to do with a baby. But, I knew how to change him because I'd seen other people changing their child and whatever. And so I didn't have no problem with that." It was Mary's comment to me "You wouldn't know since you're not a parent. But you know it when you have children," that revealed her belief that experience was fundamental to competency.

When asked what kinds of activities Mary did with Mike during his bedtime routine instead of reading stories to him, I was granted one of my rare glimpses of her mothering skills when Mike was an infant.

> I just talked, like, held him and talked to him or put him on the couch, put a pillow in front of him. Or put a blanket on the floor, and let him lay on his tummy because he plays and put some toys in front of him. And then put him in bed, you know, bathed him and put his nightclothes on then put him to bed. ... Half the time, I'd just put him in bed after I'd bathed him and put his nightclothes on. Then leave the door open a little bit, so I could hear him.

Again, it is the notion that a "good mom" always puts her child to sleep in a warm and safe environment that seems to have struck a cord in Mary's perceptions of what the role of a mother entails. Likewise, the times when Mary was reluctant to discuss her self doubts or insecurities seemed motivated by the fear of being perceived as a "bad mom." At times, this avoidance was evidenced by a change of topic mid-sentence, by getting up for a new cup of coffee and a cigarette, or by wanting to show me something inconsequential in the room. These kinds of responses represented a self preservation; her need to appear "normal", so that she would be more readily accepted by the dominant culture. All were strong motivators for keeping our conversations on topics she felt comfortable with.

Going to the school meetings, for Mike's sake.

Like many mothers of young children, Mary took great pains in ensuring that her son was well fed and warm enroute to school.

> When I took Mike to school, I used to dress him really, really warm. Like a couple of sweaters, a short sleeved sweater, and then a long sleeved sweater and, you probably know, your mother did that to you when you was young. A hat on and then a hood and gloves on, and about two pairs of socks, and then boots. And a snowsuit and scarf around your neck. My mother said that I dressed him too warm. I said well, I always make sure that he's warm.

However, when our discussions turned to what it was like for her when Mike was in school, it became quickly evident that dealing with school professionals was a role Mary did not particularly relish. This is not surprising, given her "reading problem".

> I went to some of the meetings but I find that I really didn't have to because all they was talking about was school work, but they'd practically tell me over the phone anyway. And they'd send notes home and what not, and his work home... I went down to the school off and on, but not a whole lot, as the other people.

Although there were two teachers who Mary remembers as being helpful to her and Mike, she remembers that most were not. The occasions she did go to the school were because she felt the school authorities were singling Mike out from the other children and he needed her to defend him.

> ...And I said to him, (the teacher) 'you never know if the other kid started it or not. Did you see him hitting this child, or this child hitting him?' and they said 'No.' I said you really can't blame him, and I said 'I'm not taking up for him, but you've got to know for sure if you are going to suspend my child and not the other one.'

Mary's tendency to shy away from school activities unrelated to Mike's misbehavior may be related to her fear of not measuring up intellectually. This speaks to her tendency to keep herself somewhat isolated from her community for fear of being identified as different from the other mothers. Yet her comments could easily have come from a mother who has not been labelled with a developmental disability who is cognizant of the rebelliousness that exists within most children.

> I taught him what was right and what was wrong. ... If I had matches or a lighter down on the table and if he'd go and pick them up, I said 'no, it's not for kids.' And with the outlets, I said 'no' and then I'd go take his hand and walk him away from it because I didn't have those little white plug covers. ... If he was around other kids and they got in a squabble, I

> would tell him that was wrong. It was not nice and so he would understand. Until he'd do it again. They've got to do it again. Yeah, just like we did. Right?! (We both laugh, recognizing the truth to this statement).

When Mike did get into trouble "which wasn't very often" Mary insists, she had him stay at home "with no treats." It was my assumption that the "strict mother" role she sometimes presented to outsiders was more to do with her struggle to show Mike who was boss, even if he had long stopped believing it. This became evident when Mary acknowledged she found it difficult to consistently set limits—often because of Mike's anger— and sometimes it was, and still is, easier to let things go. This is not a behavior limited to parents with developmental disabilities. In my experience, many parents opt to "let things go." They cite reasons as being "too tired," "not worth the effort," and/or "it would cause more problems than it's worth," (i.e., temper tantrums). In some ways, Mary is more similar than she is different with many of her parenting peers.

Once in a Blue Moon

"Once in a Blue Moon" refers to Mary's living conditions and social opportunities as a person living on social assistance. Just as "food" and "family" are common themes in Mary's stories, so are poverty and isolation. Poverty is a circumstance often made worse for parents because many — and Mary is one of them— will do without in order to provide for their dependents. Giving up her last few dollars so that Mike had the same runners as the other children, or so that he could go on a basketball trip, is something that occurred often early on and continues to be a common occurrence as Mike struggles to obtain his independence as a young adult.

Mary says she longs for the days when Mike was younger because in the last four or five years they do little together in the way of activities.

> Well really, when he was younger he didn't have no choice. (laughs) But now he do have a choice. And when he turned nineteen I asked him to go do a couple of things with me off and on sometime, and he tell me no. And I said, "OK, fine."

The psychiatrist who did Mary's assessment as well as two other community agencies involved at the time, all recommended long term parenting support for this family, especially after Mary's mother left Victoria. As a parent with a developmental disability, Mary was eligible to receive a variety of specialized services and opted to receive support from the "Apartment Support Program" for assistance with moving, filling out forms, cooking and budgeting. Eligible to receive parenting support as well, Mary chose not to participate in this program, indicating to me a sense of pride and independence; needing to prove that she did not require help as a parent.

> Well, I didn't go to the meetings or anything. (A monthly mom's group.) Because I didn't really, I didn't need them. Because I knew what I was doing anyway. And like I said, I know how to do everything. And I just got a reading problem, but if I needed anything to read or anybody wrote me a letter or something, my family or my friends helped me out. So… And if my family's not around, then I get Mark (apartment support worker) if he is in the neighborhood.

As alluded to earlier in this chapter, Mary's social, parental and financial support network took a catastrophic hit when her mother and stepfather left Victoria to return to Newfoundland in 1990 when Mike was just ten years old.

> In Victoria, I feel most comfortable in my own home and my sister's and my brother's. Right here, I feel safe, but I don't hardly go out at night unless someone is with me that I really know. But I don't have nobody.

Most of Mary's time is spent inside her apartment or over at a siblings' home, unless it is the last Wednesday of the month when she receives her much anticipated social assistance cheque. It is on this day, once a month, that Mary goes "shopping", an event that Mary looks forward to all month long, each and every month of the year. With only $200 to last her a full month, shopping typically involves the purchase of necessities, which Mary understands to be food, clothes and cigarettes. There are times however, when Mary will splurge 20 dollars on a pizza or Chinese food. While this may be seen by some as an example of poor judgement— and there is some truth to this— it is also important to understand that "wreckless" spending is Mary's attempt to feel like a part of society for a short time before the worry, fear and despair start all over again.

For three and a half weeks of every month, anticipating the arrival of her cheque is a daily topic where fantasy is interwoven with the realities of living on a fixed and extremely inadequate income: "If I had money, I wouldn't be living in no apartment no more. I would live in a nice cozy, small house and, once in a blue moon, I'd buy some clothes. But that'll never happen."

A new role with different expectations.

Mary and Mike have a routine these days that is all too familiar in many households. Mary does the bulk of the domestic chores, while her adult son does the occasional shopping errand or, if absolutely necessary, will prepare his own food. Establishing the parental responsibilities of an adult son is something that many parents struggle with, including Mary. "He will always be my child," she says, but having to get after Mike to keep up his end of the housework and to share the financial responsibilities, is not something she relishes. Asked how her life has changed since she had Mike, she looked up, pondering the question for a little longer than usual:

> I don't think it really changed. Well, in a way, like being a parent, and supporting him right up until he's twenty is hard. ... All he's got to do now is start buying groceries for himself, because I can't afford to buy groceries all the time for the both of us. Which I don't mind, but in a way I do. He's told me that he would, but he didn't tell me when.

These days, Mike receives frequent phone calls from girls, but insists to his mother that they aren't his girlfriends. "I says: 'yeah, yeah, that's what you tell me. But I know different'." Although she longs for the days when she and her son spent more time together, Mary is cognizant that this is a normal course of development for young adults and believes she will have done a good job as a parent when Mike has moved out on his own—even if that means that life will become even more lonely.

Over the course of my interviews with Mary, I became particularly aware of her need to veil herself in a "cloak of competency" and perhaps, to the untrained observer or in superficial dealings with Mary, she was successful in doing this. Mary also appears to have successfully taught Mike the virtues of displaying a facade to the world that hides most indications of a disability that could set them apart from their peers or casual observer.

The following ethnography will show that although Mary and the next participant, Margaret, fall into the same labelled group and share some of the same experiences— including the lack of acceptance from the dominant culture— their experiences as women, mothers and as partners are also very distinct from each other.

Margaret's World

Certainly, one of our universally lauded societal norms sees “parenthood” as an intrinsically desirable social role. It appears that there is not only the cultural expectation to have children, but that everyone should want to have them. My own status as a childless woman was a situation that both participants found quite peculiar, but particularly Margaret: “I couldn’t imagine being your age and not having any kids yet!” It was only after I explained that there was a medical reason that Margaret could accept my “predicament”. It is possible that after years of being isolated and singled out as different, Margaret’s belief is that one’s status within the dominant culture automatically improves upon becoming a parent (Campion, 1995).

Margaret is a 35 year old mother of two children, who in 1997 married a man named David. They have a son Dane (9) and Margaret has a daughter, Nicole (14) from a previous marriage. Soon after honeymooning at the “Honey Bear Bed & Breakfast” for a night, David obtained a full time job as a janitor and Margaret maintains a home in a subsidized housing complex. Although David has not had an assessment to see whether he was eligible for services, Margaret on the other hand, became eligible when her 1997 psychological assessment scored her below the 70 criteria, with an IQ of 68 (WAIS-CR).

We met for our first interview at a nearby shopping center so that Margaret could follow me in her car back to my difficult to locate home. To my annoyance, I found that I too had preconceived ideas of the kinds of potential that Margaret and other families headed by parents with developmental disabilities have in terms of material possessions.

Quite frankly, I was not expecting Margaret to drive up in a recently purchased "mint condition," 1985 Thunderbird, and I suspect I was not the first person to react this way given her slightly puzzled and unenthusiastic response: "Yes, people seem to really like this car." Margaret followed me back from the shopping center and from my rearview mirror I observed a very serious driver whose focus was entirely on the road, unlike myself.

Within the last decade, there has been a cultural expectation often referred to as the "Super Mom" phenomena. The Super Mom must be a good role model, parent, wife, school volunteer, employee or manager, "housekeeper," and so on. Mothers should be able to "do it all," and need only minimal help doing it. It has been my observation that media images of Super Mom's are especially powerful for those families who spend a great deal of time watching television. This is something that both participants said they do with their families for at least a few hours every day, as do many of the parents that I work with, as well as people I know in my personal life. With the constant barrage of images of purchases of vehicles and house purchases, annual holidays, designer clothing and good restaurant meals, many families today strive for materialistic possessions, and not necessarily the previously valued parenting characteristics such as understanding, trustworthiness, love and stability (Wolfe, 1990).

What is most distressing about the cultural expectation of having it all and doing it all, is the implication that not 'pulling it off' may result in losing one's children if the parent has a developmental disability (Campion, 1995; Booth & Booth, 1994). Certainly in this study, it was my impression that the participants understood on a conceptual level that society may judge people for what they have and will scrutinize all aspects of their parenting.

The Most Exciting Thing is the Birth of the Baby

The first theme has to do with the events leading up to and culminating in the births of Margaret's children. In a very sequential manner, and with a distinct laugh that implied a variety of emotions, Margaret's repetitious telling of the details of her pregnancies and births suggested to me that like most mothers, these experiences have had a huge impact on her. "Yes, the most exciting thing at the beginning is the birth of the child, the baby. I think that's such a miracle ..." Margaret's careful contemplation and honest self-reflections were indications of her abstract thought processes, and were especially evident in this theme.

Although she had been pregnant once when she was 17 and had an abortion soon after finding out, Margaret was nevertheless shocked to find herself in the same predicament four years later. "I couldn't believe it! I'm going 'no, no, no, no, no...' this wasn't supposed to happen at this age!" Concerns about her own lack of maturity were compounded by the fact that the relationship with her first husband was abusive. "He was an alcoholic and a drug addict who tried to keep me in his world." At the age of twenty-one "and a half," (Margaret puts a lot of significance on accuracy which accounts for her many references to "and a half"), Margaret told her mother that she was pregnant with Nicole. Given their unhappy marriage, her mother reacted badly to the news and initiated the first of two estrangements between them.

When Margaret and her husband decided to keep the baby (Nicole) she prepared for motherhood by attending "birth classes" on her own and purchased whatever she could afford in the way of baby items. Although the couple continued to have serious problems, they were together when the labour began. "I didn't know I was in labour. It was my first time having a baby and I didn't know what it felt like!" Eleven and a half hours later, Nicole was born. Very characteristic of many mothers who have just given birth, Margaret was tired but still remembers promising to herself, "I'm not going through that experience again. No way!"

Margaret's pledge that she would never again go through childbirth is a familiar comment made by most new mother's but with time, the painful experience of labour is overridden by the prospect of having another child. It is interesting to note that this was not the case for Mary. Despite marrying a man eleven years after Mike's birth, Mary said she never wanted to have more children. "I seen my neighbors with their three children, and they never had money for nothing." Her reasons were based more in the culture of poverty than memories of a painful birth.

Nicole was 18 months old, when Margaret left her first husband while pregnant with their second child. As with most troubled marriages when young children are involved, this was a time of mixed emotions. "... It was very exciting playing with her when she was little, but it was also very hard because I didn't have a good relationship with her dad and we didn't do well spending time together." Family conflicts are a pattern in Margaret's life as indicated by a number of incidents including estrangements with her mother and step brother, and the fact that Nicole was the same age that Margaret was when her parents divorced under similar circumstances. (Margaret has seen her birthfather only a few times since she was three years of age.)

Given her status as a newly single mother, Margaret opted to abort the second pregnancy soon after leaving her first husband. She reconciled with her mother and stepfather who assisted in obtaining an apartment. With the additional support of a local daycare, Margaret enrolled in a literacy course. Increased opportunities for socializing led to meeting new friends, including a man named David. Margaret describes their 10-year relationship as one that is "way different than the first one!" A "... trusting and honest," pairing, both parents agree that their main priority is to put their family's needs before their own. Margaret understands the healthy status of her marriage as the result of good communication. "David and I sit down and I let him know my opinions and he tells me what he thinks and sometimes, it gets into a big heated argument, but nothing beyond that." Margaret adds that it has been more difficult lately because Nicole is the source of most of their disagreements; the issues are usually related to her adolescent development, step-parenthood and sibling rivalry. Again, these are common themes in many families within the dominant culture.

Similar to Mary's perspective on birth control, Margaret explains that three of her four pregnancies were the result of ineffective birth control and not misinformation about usage. "There is one kind of birth control pill that doesn't make me safe. That's how I got pregnant with Nicole, the second baby and with Dane." Margaret is confident she took her pills at the right times, so when Margaret discovered she was pregnant with Dane, and within four months of meeting David, she was shocked.

> I didn't think about it when he (the doctor) gave me the pills. I just started taking them. And then, you know how—I don't know if you know what pregnancies are like. ...well with me, your breasts usually get sore first. And I thought no, I can't be, I'm on the pill. And a few days later, I knew

> my monthly was getting close and it went by and I gave it a few more days. I went to the doctor and I said I think I'm pregnant and he says 'are you taking the pills', and I says 'yeah'. And then I pulled the pills out and I realized, I'm on the wrong pills! And I go, I'm on the wrong ones you, ... I didn't call him an idiot, but I felt like it!

It appears that Margaret is unable (or unwilling) to see any patterns in terms of taking responsibility for the unplanned pregnancies. While Margaret may truly believe that she is "immune" to a certain kind of birth control pill, it is more likely that by denying responsibility for the abortions, she is able to separate herself from emotionally attaching to the child growing inside. When she became pregnant with Dane at the age of 25, Margaret was certain she did not want another abortion and told David how she felt.

> ...I sat David down, and I said: 'we've got a problem.' ... I said, 'I'm pregnant'. And he looked at me, like in shock. And he says, 'but he put you on the pill!' and I said 'well, the doctor gave me the wrong pill'. I said 'but there's one pill I can get pregnant on, and this is how I got pregnant with Nicole.' I said to David, 'If you want, you can be by my side', and he of course, wanted to.

This time and with her mother's support for her right to choose, Margaret and David told the doctor that against his recommendations, there would be no abortion. Given Margaret's belief that all women should want to have children, I wondered if the certainty of her decision to keep the baby after just four months into her relationship with David was based on the belief that becoming pregnant was the appropriate next step in a good relationship. Upon hearing Margaret and David's decision to keep the baby, the doctor turned to Margaret's mother to persuade the couple to reconsider.

> ... I felt this was my decision, not my mother's, and if I decided to keep the child that's my decision. And my mom stuck behind me. She said to my doctor, 'I can't tell her what to do. She's an adult. I'll support her and help her make the right decision, but it's her decision.

Despite the doctor's reservations, (Margaret did not know why the doctor didn't think they should have children), David and Margaret did not change their mind— or doctors. "... we got through to him. David would come to these appointments with me, and we told him: 'this is what's going to happen and we're having this baby, deal with it'". As illustrated by my early experiences with the care provided to the young autistic boy at the residential centre, many cultures continue to see medical doctors as authority figures and will agree to, or be unable to dispute medical decisions and/or procedures that may not be in their own best interest. David and Margaret's decision to keep their baby was a decision they felt was their right to make, regardless of the professional advice that went against their decision. It was an assertive stance, not uncommon, but not required of most individuals in the dominant culture.

Three months into the pregnancy, Margaret said she knew she was having a boy because it felt different. "I was bigger, much bigger!" During the first trimester Margaret tripped on a broken "boot lip" and fell hard onto her stomach. Kept overnight in hospital with baby monitors strapped to her stomach, Margaret was released under the condition that she stay in bed for a month. The pregnancy seemed to return to normal and in her sixth month David and Margaret began to attend "birth classes", even though Margaret did not see it as something she needed. "Been there, done that. But he (David) wasn't feeling so secure so I went through it again because I love him." Just before Christmas, nine months into her pregnancy, Margaret began to go into labour.

> ...That night, David and I ended up doing the rest of the wrapping presents and he finally convinced me around three o'clock to go to bed. I had been sleeping on the hide-a-bed, because we had a waterbed that I couldn't get out of in the mornings because I was so big. (Laughs) But he convinced me (to sleep with him) by promising he would help me get out of bed in the morning. My first labour with Nicole, my water didn't break and had to be broken. And so when it broke with Dane, as I was getting into the bed, well I wasn't sure about this. I go 'oh shit, I've got to go pee', and I started peeing myself! Well I didn't know it was my water because it is totally different when you get it broken for you and when it breaks on its own. So I get back into the bed and it started to happen again. You feel like you are peeing yourself! By the third time this happened, I was on the toilet and I'm starting to get pains.

Acting much like the classic first-time father who has just been informed that his wife is in labour, David ran around in circles causing Margaret some irritability with his repetitive questioning of whether it was actually time. "I yelled, 'I'm very positive I'm in labour', I said 'this is the water breaking, I'm very positive of this', I was sure what I was talking about!" As the time for the birth grew closer, David alternated between being the doting, helpful husband to one in sheer panic mode.

> Well it was the first baby he has had, but it's my second and it's like 'what's the big deal here?' We got to the hospital and I was already three centimeters dilated and I had him, eight pounds two and a half ounces. It was only four and a half hours labour! Yes, the most exciting thing at the beginning is the birth of the child, the baby. I think that's such a miracle because they're not always the same when you give birth from one child to another. It's totally different.

Discussed further in the section, "Life's Challenges," Dane was different from Nicole in many ways including the fact that he was born with a number of significant disabilities, the cause(s) undetermined from the information available. Other differences included Nicole was only breast fed for six months before Margaret's milk inexplicably dried up. Therefore, Margaret was very pleased when she was able to breast feed Dane for longer. "I thought I'd never dry up! I used it for seventeen months until he started to bite too much. And wanting it too much."

Margaret's labour and birthing processes do not differ much from what other women have said to me, including those without disabilities. With the first child, it is not uncommon for there to be some initial uncertainty regarding labour pains, the father's reaction, breastfeeding ability, etc. Margaret's uncertainties about her water breaking seems to be more related to a lack of experience and education, than a developmental disability. The lack of education around childbirth was also true in Mary's case, which may have been the reason for the heavy medication that she received. It also could have been protocol in those days. While it is difficult to make a judgement about which was a "better" situation, it is especially interesting that in the birthing experiences of these two participants: a) Mary had much less support, if any, during such a painful and frightening time, and b) Both Mary and Margaret perceived their experience of giving birth as a "certificate of competency": Having a child = being able to parent.

The Duke of Edinburgh Awards

Theme two examines how Margaret frames and makes sense of her developmental disability. "The Duke of Edinburgh Awards" is a reference to a Physical Education examination that was part of the Canadian school curriculum in the 70's and

80's. The level of a child's physical abilities was determined by engaging in a variety of stamina and coordination tests, with scores having to fall within a certain range to qualify for the Gold, Silver or Bronze Awards. As I remember it, these tests required higher levels of physical fitness than was typical for children at that time. Many non-disabled children were unable to achieve even the lowest criteria (Bronze Award) and Margaret too, remembers this childhood event as a particularly embarrassing and frustrating experience and one in a series of negative learning experiences.

Margaret recalls being in a special program since "day two," where she attended several different schools. Margaret describes her disability as:

1. Being unable to read very well, and not at all when she was in the "special classes" at school.
2. Being unable to remember much of what she is taught unless "I am shown how to do it, then I get it."
3. "... not being able to figure things out sometimes."

From the age of fifteen until she was eighteen, Margaret attended a program geared towards the needs of children and youth who had developmental disabilities. Margaret indicates very clearly that she was not at all satisfied with what the program had to offer her.

> I didn't get the stuff I needed for life. It was really more for kids that had more mental problems. Like I have a few problems, a few, but not that much. I found Science and Social Studies weren't any good to us. When were we going to use them in life? But Math and English, that kind of stuff comes into effect in our lives. But they (the teachers) tried their

> best—except for the 'Duke of Edinburgh Awards'. I mean, that was a complete waste of my time! A total waste of my time!

Asked what other skills would have been more useful in her school program, Margaret was convinced that practical life skills would have benefited her as an adult.

> Social skills, like being out there a little more in the community. And like learning how to balance a cheque book and how to do housework, because I didn't get that at home from my mom or dad. I had to learn all that kind of stuff on my own.

Margaret attributes the cause of her developmental disability to a childhood physical disability, inadequate training and a lack of appropriate role models.

> Because I'm illiterate; I can't read very good and have problems from growing up because when I was born, my vocal chords were small. They didn't stretch it until I was ten, so I couldn't talk. And if you think about this, if you can't talk, why are you going to want to read?! So I went back and had to take speech therapy when I was little. That interfered with my college program and different stuff, but then I met David.

Margaret has always had a strong sense of independence including the acquisition of a driver's license at the age of sixteen. Although regretful that her mother did not provide her with more opportunities to learn important life skills, she is grateful that she taught Margaret how to drive.

> Mom worked for 'Young Drivers of Canada' and she explained to them that I had a reading disability, and we dealt with it. They would read the questions to me, but wouldn't give me which answer it was. I had to figure out that for myself. I passed that on the first try, but the driving test took

> me two tries to do. ...It's coming up to twenty years this year that I've had my driver's license.

Margaret cannot imagine being unable to drive because it has enabled her to do certain things with her children that she would not have been able to do otherwise. Just as with Mary where food represents competence, Margaret's license represents her independence, freedom and mobility.

While Margaret says she is basically illiterate, she considers herself "very computer literate."

> We've got a 386, 3.1 computer in Dane's room that the kids share. One day we want to upgrade it like our Windows 98 computer in the living room. And we're on the Internet with Shaw cable. Of course, we wouldn't go phone line, that's too bloody slow. That's like snail mail! (laughs) And we've got email.

Family-oriented activities are extremely important to Margaret and David, and the computer is something they all love to do. "Going online" involves visiting various websites that include "kids.com," various game sites and individual interest sites. (i.e., Margaret likes to keep up on the events of her "soaps" by going to "ABC.soaps.com" after the children are in bed.) Although it takes reading skills to web surf, Margaret does better online than reading a book because the requirements for comprehension are less demanding. In the case of her "soaps", she can rely on memory for what function certain 'buttons' play and is only required to read short sentences and brief synopsis. (i.e., "The Young and the Restless—Friday Updates") Like Mary, Margaret's reluctance to acknowledge the support she has received from many agencies since moving to Victoria in 1996, suggests that Margaret relies more on David and Nicole in terms of her reading and parenting skills than she is willing to admit.

Consumerism on a Poverty Line Income

Like many in our culture who are marginalized, finances have always been a struggle for Margaret. As a family of four trying to manage on disability benefits and David's janitorial job, any additional money (eg: Nicole's trust fund from Victim's Services and a recent inheritance) has been spent long before it is received on "luxury" items. Like Mary, Margaret and her family endeavor to be "just like any other family", by participating in recreational activities and by making material purchases, (i.e. two computers, a Thunderbird automobile, a Total Gym "1000," etc). In the process, they have at times overextended their credit limits, had their hydro and phone disconnected, and have little left over for emergencies, extra-curricular school activities, or respite (i.e., babysitters). On the rare occasion however, Margaret has exchanged child minding favors with a few of her neighbor and friends.

> "I looked after my girlfriend's little one during the day so she could clean up her house. And then when she looked after my son, Dane, she asked if he would like to stay the night and I'm going "YEAH, YEAH!" I know he would! ...I find I need a break about once every three months."

Financial mismanagement has been a recurring theme with this family since their first involvement with the PSP in 1997, but they have found ways in which to deal with this situation. "We go do groceries together because we've got nobody to leave the kids with, so it's usually the whole family that does it. We go out to Costco and you can eat at the same time out there!" Since David could stay home and Margaret could shop, (or vice versa), it seems clear that this is one option Margaret and David have found that effectively deals with the limited resources available for entertainment and “treats”. In reality, inappropriate material purchases are familiar to the dominant culture as well. The only possible difference is that like Mary, Margaret seems less aware of the short and long term consequences of her financial decision making.

You Sort Of Learn As You Go!

Margaret feels strongly that her learning as a parent came simply by doing. Each challenge she has faced as a parent has been “dealt with” as the situation arose. This premise is consistent with the literature: that most parents who have developmental disabilities are better able to integrate the skills they require when they can learn, practice and apply them in real life situations (Feldman, 1986; Tymchuk & Andron, 1992; Personal Experience). Margaret maintains that she did not have support from anyone when her children were first born, nor as they grew older. “I just learned all on my own, as I went. It’s not something that you just have the knowledge of; you just learn as you go.” Wanting to explore this a little more, I asked Margaret how she had learned to make formula without help since she would have been unable to read the instructions. “Well it’s pretty standard and simple!” after which she changed the subject, ending any further conversation. I wondered if this too was a skill she had "learned as she went". When I began asking direct questions about the kinds of professional resources she has been involved with since becoming a mother, Margaret then elaborated about the various kinds of support she has received.

As mentioned previously, Margaret is quite comfortable talking to people about having a developmental disability, although at times it was difficult for her to describe how it directly affected her parenting. In our interviews, Margaret attempted to portray a high level of self-confidence when discussing her parenting knowledge and skills. (This relates to the "Cloak of Competence" as discussed in Mary's section of this chapter.) Even after I suggested that most new mothers feel nervous at first when faced with the care of a new infant, Margaret reiterated her belief that parenting is not difficult and that she did not find the experience to be a big deal. Margaret may not remember having self-doubts about parenting a baby or an adolescent, however I tend to agree with Asch and Fine's (1988) assertion that women with developmental disabilities typically lack self confidence as a result of an emphasis placed on what they <u>cannot</u> do by people these women have been supported by both personally and professionally. Somewhere along the line, perhaps before Margaret was placed in the wrong class since she "… didn't have mental problems," Margaret heard the message loud and clear that she was not competent.

Over the last fourteen years, Margaret has found that important parenting skills and responsibilities included ensuring that: the children kept clean bedrooms, had consistent bedtimes, knew "the value of money," attended church and showed respect towards their parents. Discipline on the other hand, is an area that Margaret and David have struggled with for many years and while they continue to seek out advice in this area, they feel disillusioned by the advice-givers. Margaret feels that they have "done exactly what the professionals say," but nothing works.

Nicole has been more difficult to manage than Dane up to this point in time and after various strategies that have included talking to their children about the reasons for their concerns, counting to three, and using natural consequences, Margaret and David have decided that corporal punishment, “the paddle stick” as they call it, is the most effective strategy.

> We’re the kind of parents that believe in the old way. Like spanking, well it’s like a spanking is ok as long as you don’t leave bruises. And that’s been, it seems to be, the only way it works with Nicole right now. It just works better for us. ...I just have to bring it out with Dane and he listens—I don’t even have to go near him with it because he’s seen Nicole get it a few times and he doesn’t want anything to do with it. She’s a bit more of a challenging child.

In the context of cultural changes, it is only in the last ten to fifteen years that spanking has become “bad parenting.” Some parents from the dominant culture still choose this form of discipline, perhaps a holdover from their own familial situation. This was true in Margaret’s childhood, as it was in mine. In grade five, I learned at school that the strap was an acceptable means of discipline when my father chose not to intervene in my punishment for playing with water at the fountain when I had been asked not to—even though he did not use corporal punishment methods himself. I received the strap for this “misbehavior.”

Margaret commented more than once to me during our interviews that she has found Nicole’s adolescence to be more difficult than either child's previous stages of development. The easiest time for raising children was when they were young, she explained, “... because you didn’t have to chase them everywhere. You could keep, confine them and they wouldn’t talk back!” Remembering the temptations and outcomes from her own adolescent encounters with boys, Margaret tries to monitor Nicole’s activities with her peers, particularly with the boys. “I told her, we’re not going to fool around with fire, I remember what it was like being a teenager. Mom's not stupid!" However confident that Nicole will develop into a responsible young woman, Margaret finds herself too often the recipient of Nicole's newfound independence.

> I don't mind her having a backbone, but don't use it with us. Because you are not going to win. It's alright for her to have it, but also give me respect and do the stuff that she's supposed to. Like, clean her room, do the laundry when I ask her, because she's not doing as many dishes as she used to. And so I've given her a few different other things to do now to make up for what she used to do.

While Margaret understands that spanking is not a popular strategy, she has a conceptualization of what is acceptable discipline and believes she stays within that range. Thus her comment "... spanking is ok as long as you don't leave bruises." In my experience, parents who still believe that spanking works may not have alternative methods of behaviour management. Having said this, the recent Supreme Court of Canada judgment that upheld the right of parents and teachers to use corporal punishment, suggests otherwise.

In true "learn as you go" fashion, Margaret has struggled with the conflicting emotions often associated with family sexual abuse allegations but has found that through professional counseling and talking with other families, things are much better now. A very traumatic period of time for this family, Margaret is convinced that family therapy was instrumental in helping them to understand that the abuse perpetrated against Nicole at age five was not something anyone should feel ashamed about. Counselling also helped Margaret to come to terms with her ostracism from some of the family, (allegations about Nicole's abuse resulted in the second estrangement from her mother and continues to be unresolved). It is commendable on Margaret's part that in the most healthy and positive way possible, she was able to recognize the need for professional support in order for herself and Nicole to deal with the issues related to the abuse and the subsequent fall out.

Learning as you go has included the use of new technology. With computers such a big part of this family's entertainment and as cyber crimes against children increase, Margaret and David have done what many parents are now doing to monitor their children's computer use: they have relocated the computer into the living room and installed child protection software. "...Because otherwise, that's the way kids get into trouble." Despite these precautions, it is still possible for kids to get into inappropriate sites, which raises the question: What will Nicole do when she catches on that she can fool or mislead her mom and get into computer sites or places in the community she should not be in? As is typical in adolescence, parents are believed by their children to be "stupid," and it is natural that they test the boundaries. It will be an interesting time for Nicole and Margaret's relationship as Nicole becomes more aware of her ability to mislead her parents, possibly trying to pull the wool over her mother's eyes, and perhaps even more so than what is common in most families.

While Mary has already struggled through Mike's rather difficult adolescent stage, Margaret is obviously just beginning. Parenting today is much different than when Mary was parenting Mike ten to twenty years ago. Families are eligible for more support although funding is not always available. Regardless of whether Margaret does get more support than what Mary did, it will not likely be any easier for Margaret given her youngest son's special needs and her daughter's history of sexual abuse. What may work in this family's favour, however, is that Margaret has an expectation that she is entitled to certain supports and that they *should* be made available. This is evidenced by her many comments to my colleague and to myself that it has been difficult to get the services they need and that she's had to fight "... tooth and nail" for everything they have received thus far. While it is not unusual to meet those who believe it is an inherent right for individuals in our culture to have a social safety net, there are also many on the other hand who are like Mary and don't have high expectations of what they may receive.

Life's challenges.

"He's considered a light gazer. Like at Christmas time, you should see his eyes!" A few months after Dane was born, Margaret's doctor diagnosed him with a number of significant developmental and physical disabilities, including a severe vision deficit. But it was not until Dane was ten months old, when he received his first pair of glasses, that Margaret began to accept the reality of Dane's situation. At first, she did not think she would be able to handle the responsibilities of caring for a child with special needs but soon began seeing past his disabilities to appreciate and focus on his strengths. With extreme pride, Margaret reports that her son is "…a good student," "… a better 'vacuumer' than Nicole", but that best of all "...he is a momma's boy who still likes his hugs from daddy!"

> Yeah, he's been wearing glasses for a long time, and now he's got a few problems being in school, like he's quite delayed. I would say he's two years behind from where other kids are, but he's coming in there. His printing is getting nicer and he's starting to read, and I'm very pleased with that.

Margaret's pride in her son's increasing ability to read is perhaps a reflection of the importance she now places on literacy after her own life experiences where many difficulties resulted from not being able to read. Supportive and excited about Dane's progress with reading, Margaret seems committed to breaking the pattern of illiteracy within her nuclear family. It is interesting however, given Margaret's appreciation for literacy training and professional counselling, that both she and David are still quite distrustful of professional intervention. In a report made by the psychologist and interdisciplinary team involved with Dane's assessment in 1998, many of the comments in the report angered the couple. Although she could not remember any specific points, she did not feel it accurately represented the problems their son has. "Like, tell me how you can write a report about someone that you've only met twice. No way you can write a report like that. We just disagreed with the whole thing."

Although psychological assessments can be very useful tools with which to understand and plan for children who have special needs, there are valid aspects to Margaret's concerns as psychological assessments and evaluations do have their limitations. As stated in Chapter One, basing one's needs, service eligibility, and financial benefits on the results of a simple IQ score does not recognize the "client" as an individual with distinctive needs, history or experiences. An individual with an IQ of 58 is likely to operate very differently in the world. However their level of dependency and ability to problem solve will have also been based upon their experiences growing up, what was going on in their families, what they saw was acceptable and unacceptable behaviour, and, what their financial situation was.

Margaret's perspective about her situation as a mother of a special needs child is different from what you might typically see in the dominant culture where people tend to think that others always have it better than they do or that the "grass is greener on the other side." On more than a few occasions during our interviews, Margaret compared her own situation to her neighbor's who is the mother of a child with Down's Syndrome. Margaret is in awe of this mother and her ability to cope. "I can't imagine having her! Even when she comes over for a little while to our place, she's a big handful!" While children with Down's Syndrome have their own set of unique problems, Margaret sees this child as being much more difficult than her own son, despite Dane's multitude of physical and developmental disabilities that are in my opinion, more challenging than her neighbor's child. Perhaps as a form of self-preservation, Margaret has chosen whenever possible to see other's lives as more difficult than her own.

Currently, Dane requires full time support at home, which Margaret provides on her own without outside help. At school, Dane has a Special Aid Assistant. Echoing the cries of many parents who have children with disabilities in British Columbia, Margaret's heartfelt frustrations with the lack of funding and long wait lists for children with special needs, have been ongoing.

> ...Trying to access help for a child that has special needs is not easy, it's not accessible. You've got to fight for it. And every tooth, fight tooth and nail to make sure your child gets the help that they need, or stuff that they need, or so the parents have a break occasionally. Trying to get that kind of stuff, it's not easy.

The fact that Margaret has put so much energy into Dane's progress but has never learned how to write herself, suggests two possibilities: (a) Although Margaret was generally quite open about her disability, she has never really seen her own limitations as all that significant, as stated earlier in this chapter, when she was in a "special class," the same kind that Dane is in now. (b) Margaret may feel partially responsible for the fall she had while six months pregnant with Dane, (even though she has reiterated that the doctors tell her this was not the cause of his disabilities), and wants to make things better for her son.

When Dane first began attending kindergarten, Margaret needed support professionals to advocate for them at parent-teacher meetings. (There were only a few meetings regarding Nicole.) As the need to attend these meetings increased with Dane's maturation, Margaret's ability and comfort level in meeting with school authorities and other social service professionals has also increased. Advocating for her son has included:

1. Petitioning Dane's school to paint the playground steps, basketball poles, and volleyball poles, yellow. "...it was just getting it done and making sure it was done PDQ." (With the help of CNIB).
2. Meeting with Dane's Special Aid to go over Dane's goals. She also writes in a communication book (using "plain language.") about Dane's weekend and/or evenings.
3. Supporting any opportunities for Dane to be "out in the community," and often going on fieldtrips to help supervise the children.

It is interesting that both participants—Margaret who is willing to fight "tooth and nail" for support services, and Mary who would go to Mike's school when he was having behavior problems — were both willing to do whatever was necessary, despite the intimidating environments they were forced to operate within. As for many parents, the motivation to advocate for one's child seems to take precedence over everything else.

Learning once again from experience and motivated by her commitment to increase Dane's opportunities for learning, Margaret has become tenacious in providing a structured routine. "...He goes to bed early, the same time every night, otherwise they don't get any work from him at school. It's hard for them to get him to do stuff if he's tired, he's just not focused." There are times however, that Margaret says she gets weary of anticipating Dane's every move in unfamiliar situations, but is aware that she will need to do so for many years to come. "Oh, yes. Oh, yes. That's the way it is, and he's my child. So we'll go one day at a time and just keep struggling at it." Most cultures would agree that "family" is about love, support and commitment— and Margaret is certainly meeting those criteria.

Summary

In this section I have explored a few of the ever changing and dynamic cultural factors that the participant's stories are embedded in. Poverty vs. Consumerism, Isolation vs. Connectedness, "A Reading Problem" vs. "Just Like Any Other Family" are all themes that emerged from the participant's stories of their mothering experiences. I have looked at the common threads that exist between two women facing some of the challenges that many women face in today's world: the roles of motherhood, income provider, wife and all around superwoman. For Margaret and Mary, both having come from abusive childhood's, intimate relationships that were unhealthy and brief, (aside from Margaret's relationship with David), and low economic status, their fates may have been sealed before they became adults. Opportunities for career, family and wealth have not been as available to them as they are to women who are part of the dominant culture, yet both of these women have struggled to obtain their independence. They share the need to maintain a “cloak of competency,” appearing as normal as they can for both their own sakes as well as for their children’s.

Taking responsibility for the choices and/or decisions that each woman has made can be a difficult concept and may have limited their ability to learn some of life’s lessons that often come as the result of self-reflection. Margaret and Mary share the view that it was “faulty birth control” that caused their pregnancies. While struggling with whether or not to continue some of their pregnancies, both women went through the same kinds of thinking in their decisions to abort and the associated emotions that many in the dominant culture do.

While both had some difficulties dealing effectively with professional people involved in their children’s lives (school, medical), in varying degrees, Margaret and Mary feel that society has a responsibility to offer support to them. This feeling is consistent with the laws of our government and the principles of our social service provision. However, they do not necessarily accept responsibility for or take an active role in maintaining a stable economic environment for their families. They are caught in the clash of values that dominate our society; materialism vs. the rights of all to a minimum standard of living based on income.

While Margaret was very open and willing to talk about her disability, Mary tended to avoid questions that pertained to her disability unless I referred to it as her “reading problem” or talked about my own academic weaknesses. Margaret tended to be more comfortable discussing her issues and demonstrating her ability to think in the abstract. She is better able to communicate and verbally express herself. Although Margaret has a higher IQ score than Mary, it is questionable whether this alone would account for her more developed verbal abilities. Margaret is the more social and involved of the two; but we do not know how much of Mary's life conditions (i.e., social isolation and poverty) have been a contributing factor in her limited language and social development.

Margaret in many ways equates her independence with her ability to drive a vehicle. She revels in the freedom she finds in getting into her car and going where ever she wants to. Mary gets a sense of independence on the third Wednesday of every month when she receives her social assistance cheque and feels confident enough to go to the local grocery store without a friend. Margaret wants to continue looking for work that is meaningful, yet Mary does not seem to feel as obligated, perhaps as a result of being raised in an earlier generation where there wasn't an emphasis placed on independence for women. Both participants have received support over the years from family and social service agencies and have vacillated between being adamant that they learned on their own and acknowledging that they had received assistance. These acts of independence support their identities as individuals who can manage on their own.

The experiences of women who are financially disadvantaged do not differ greatly from those without disabilities. For some, poverty on it's own can present a much larger obstacle than having a developmental disability, although there are some mothers with developmental disabilities who live in poverty who do not have the ability to tap into creative budgeting plans, long term housing, and other support networks. Poverty and a lack of resources is the real challenge, not just the developmental disability.

Chapter Five: Discussion

> In the course of being human, every individual grows up into a social world and acquires competence in at least some of the cultural systems of his or her immediate environment. But it is equally true, and critically important to recognize, that no two humans ever experience the world in the same way. No one gets it all; no one needs it all. (Wolcott, 1999, p. 322)

I was captivated by the participants' unique stories, motivations, and decision-making processes, and by the contrast of Mary's fragile self-image with the strength of Margaret's. As I listened, it became apparent that these mothers are not acting in any aberrant manner, but are following a developmental pathway that is a complex, individually experienced event. Each participant embarked on motherhood under her own unique set of circumstances, motivations, and assumptions about her world, her future, and her own personal experiences with mothers and motherhood. They are linked only by their 'common circumstance' of being identified as a mother with a developmental disability.

The purpose of this study was to explore the question *"How do mothers with developmental disabilities make sense of their parenting roles?"* Specifically, I wanted to know: (a) What do mothers with developmental disabilities identify as key roles as caretakers? (b) Are the participant's experiences and understanding of their parenting roles, ontologically based? These questions appropriately formed the basis of the study and directed the interview questions. In an effort to shed light onto these issues from an insider's viewpoint, and through the use of inductive reasoning, this study described how the participants' viewed their mothering experiences.

There are two key findings that emerge from this study:

1. The ways in which parents with developmental disabilities make sense of their parenting role seem to be shaped by societal norms and cultural expectations. Therefore, it is not surprising that their experiences as parents parallel those of the dominant culture. However, society's institutions insist on making mothers with developmental disabilities different by virtue of their disability and imposing different standards, for example, the requirement for an IQ that falls below the norm, rather than an assessment of individual parenting skills.
2. In addition to individual and familial characteristics, parenting is affected by the systemic influences of social, economic and educational environments, including the inter-related themes of poverty, literacy and life skills training.

Culturally Constructed Roles

What does a traditional family look like? The literature suggests that considerable flexibility is necessary when defining family in Canada because at present the institution takes many and varied forms (Burt, Code & Dorney, 1993). What was representative of a family ten to fifteen years ago is much different today with the increase in blended families, single parents, and lesbian/gay parents, to name just a few. Regardless of these changing definitions of family, mass media continues to peddle nostalgic images of family life that consist of two heterosexual parents, 2.3 children, stay-at-home mom's and the proverbial white picket fence.

> …images abound ranging from the 'Father Knows Best' family; the family we think we remember from childhood; or the family as sanctioned by the Bible, the Koran, or the Torah. It is seldom, if ever, the family in which we actually live. (Burt et al, 1993, p. 423)

The power of these idealized images is such that we can long for Mom's apple pie and times gone by, even if Mom never made apple pie. These images influence the ways in which individuals are valued and judged in the maintenance of culturally accepted roles, including that of the "Super Mom" phenomena discussed in Chapter 4. In a study that makes comparisons between men and women with developmental disabilities, Walsh (1988) notes that "...these women achieved significantly higher scores than their male counterparts in performing household tasks, such as making the bed, setting a table, and taking care of the kitchen" (p.168). Walsh concludes by saying "...it seems likely that the presence of a mental handicap does not exclude women from traditionally gender-specific duties" (p. 179). Again, the similarities between the mainstream culture and that of parents with developmental disabilities are apparent.

In my own experience, professionals working with people with developmental disabilities are generally in agreement that the challenges vary for families within the dominant culture as well as for those who are developmentally disabled; that there are more similarities than differences amongst these two groups. Based on the information I obtained in this research study and my 20 years experience working with people with developmental disabilities, I do not believe that mothers with developmental disabilities have established what could be considered a unique culture or sub-culture within, or separate from, the dominant culture. Supporting this belief, is that neither of the participants in this study gave any indication of a need to have their own "culture" for which to be embraced by. Rather, both moms had a strong desire to be part of the mainstream. While each woman experienced her own degree of success in accomplishing this, it was her skill development and understanding of the parenting role that allowed her to believe that she was living up to her ideal parent model. As referred to earlier in Chapters Two and Four, Mary and Margaret's self-esteem, previous life experiences, family of origin experiences, all aided or abetted in certain aspects of their skill and knowledge development.

These factors may change more favorably over time as society moves to better funding structures that support community participation and the integration of the various marginalized groups into the dominant culture. In my opinion, the process of de-institutionalization and the subsequent outcome of having people with developmental disabilities integrated into the community, allows society to develop and group together people with shared interests, instead of grouping people based on cognitive or physical ability. An example of this would be the sub-cultures that have evolved within the deaf community. It was common many years ago, to send children with hearing impairments to residential schools for the deaf. Many of these children would spend their entire school years together and away from their families. At graduation time, the students would return home to their families or be absorbed directly into the community. Having lived most of their years in an institutionalized setting, integration was difficult for many of these students. This group of individuals developed coping mechanisms and partnerships amongst themselves that offered a safe environment. From these experiences a "deaf culture" emerged. Membership in this culture came about based on one's attendance in a "regular" or "special" school and on the type of language used (ie American Sign Language vs. Signed English). While there are some marginalized groups within our society that appear to have established their own "culture", I do not believe that parents/mothers with developmental disabilities have. However, if they begin to form the same types of alliances currently seen in many other marginalized groups, we may then see the emergence of a sub culture.

Given the conflicts built into the modern family, along with the expectations of the dominant culture and of individual family members, the involvement of community organizations and the fictional versus true images of the family, it is hardly surprising that there is considerable confusion around these roles. Hartrick (1994) asserts that a central component in "motherwork" is maintaining the overall stability of the family. If a woman does not feel stable (and healthy) in her self, it would seem unlikely that she would be able to provide this overall stability for her family. As discussed in Chapter Two, instability in some mothers with developmental disabilities does not just evolve from "rolelessness", but from years of failure, the stigma associated with special education, being teased by peers, and the realization that one's abilities are limited (Ashe & Fine, 1988). Other factors, also previously discussed in Chapters Two and Four, include socio-economic circumstances, life experiences, and accessible resources, are also significant (Tymchuk, 1990; Llewelyn, 1999).

As described in Chapter Four, Margaret and Mary's attempts to conceal any uncertainties they may have in their various roles, including parenting, closely parallel what Edgerton (1967) refers to as the 'Cloak of Competency' phenomena. Even for many parents in the dominant culture, there are times when it is difficult to mask the difficulties of parenting with the calm contentment of motherhood as it is often depicted in the advertisements. Mary struggled to appear "just like any other family…" but felt unable to adequately support Mike in his educational needs or maintain a home that could be considered reasonably tidy by anyone's standards. Margaret was concerned about keeping up “the super mom” image, and although she accomplished this quite well under the circumstances, she lacks the organizational skills required to manage household finances, the increased physical and emotional needs of her severely disabled son, or the typical challenges of adolescent behavior. Mary believes that 'family is everything', whereas Margaret seeks support outside of her family.

Due to the changing faces of 'family' in the 2000's, Mary and Margaret do not stand out as much as they would have twenty years ago for reasons noted at the beginning of this chapter. Herein lies a paradox coming from the contrast between the participants often ingenious and strenuous efforts to 'blend in' with the dominant culture and their dependency on professional supports.

As was discussed in Chapter 2, Rutter (1983) defines parenting as the ability to respond to a child’s basic needs, to love and undertake relationships, to care, support and nurture other people, and to communicate. Campion pushes the definition of parenting further with the assertion that there is an "ideal" versus "actual" cultural expectation of "fit parenting" (1998, p. 168). The "ideal parent" is one who must conform to the dominant culture by having a secure job, and 'good' home. Society's norms indicate that ‘ideal’ parents must also be able to maintain motivation and consistency in the following parenting skills: reading, providing nutritious meals, telling time, developing household and child routines, understanding and responding to safety issues, knowing various discipline strategies and responding positively to children at frequent intervals, having self control, playing responsively, being open to ongoing learning, understanding developmental milestones and needs, providing cognitive stimulation, and helping with the formal education of the child, (ie: homework and participation in school activities).

Campion argues that while the above components to parenting are significant for a generic understanding of the parenting role, the following list of 'actual' parenting skills is a more accurate representation of the requirements of the dominant culture as well as for mothers with developmental disabilities:

> 1. The skills deemed necessary to raise children depend on the nature and complexity of the environmental and social demands to which both parents and children are exposed.
> 2. Parents may require training to acquire some of the above skills so that they are seen to be good enough parents on the terms of the dominant culture. Clear and achievable objectives are critical.
> 3. Parents and children benefit from continuity of location and familiar people around them.
> 4. Parents and children benefit from the acceptance of those of the dominant culture but it may not be critical to the quality of parenting.
> 5. Some parents need more support from friends, family and statutory services than others do in order to provide good enough parenting.
> 6. Parental self-esteem is critical to how well they parent.
> 7. Parents' own personal histories are significant in how well they are able to parent. (1995, p. 167)

These "actual" parenting skills further illustrate much of the literature reviewed in this study and I have found them to be true in my own work with families headed by parents with developmental disabilities. Mary's unwillingness to participate in parenting programs could have been due to her discomfort with the label associated with a program set up specifically for parents with developmental disabilities, conflicting with her need to fit in with the dominant society. Perhaps if the program had been presented as a program that *all* parents need, she would have been more receptive. It is afterall, more common for parents in the dominant culture to seek out programs that are specific to the problems they are experiencing, (ie: "How to talk so your kids can listen: How to listen so your kids can talk"; "Tough Love", etc), rather than a program that suggest the parent is lacking in all areas of parenting.

With the parenting experiences of mothers with developmental disabilities described almost exclusively by outsiders, I have found that the development of policies, practices and resources do not always reflect parents "actual" needs. The goals of the agencies providing or "recommending" services often contrast with the needs and goals of families headed by parents who are developmentally disabled. There are a few reasons for this:

1. The agencies' definition of "good parenting" is often in contrast to the parent's definition. For example, good parenting judgements are based on the worker's own values and beliefs. Perhaps for some workers, good parenting is found in those families who have tidy homes, interact with their child for at least three hours a day, and who make all their children's meals using fresh vegetables and fruit. However, these kinds of standards are not always financially feasible and/or congruent with the family's own culture, values and beliefs.

2. The intervention plan developed for the family is deemed by the parents as *too* "supportive" and not always relevant to their needs. Some families discover that the level of intrusion and the goals defined are not what they had anticipated when they initially agreed to or sought out assistance. Therefore, parenting programs need to look at long term planning that facilitates inclusively planned interventions. Such as real involvement in goal setting, a clear understanding of the supports currently in place, (i.e., for how long and for how often), and long term planning that facilitates stability in the family's living, financial, educational and vocational environments.

Mary's impoverished background, the ongoing strong family support she depended on, some difficult past experiences and a low self-esteem, have all contributed to the ways in which she constructs her parenting experience, and to the level of her parenting skills—some of these factors have had a more negative than positive influence. One of the results was that Mary, like many other parents, was not open to any kind of parenting support. Just as with any family, the contexts in which these participants' understand and manage their parenting roles are complex and distinct. They are the result of their own vast life experiences, with personal values and beliefs that often result from religious convictions, childhood and adult life experiences, and socio-economical conditions (Espe-Sherwindt & Crable, 1993; Feldman, 1986; Tymchuk, 1990). Although it is difficult to obtain reliable statistics, the indications are that mothers with developmental disabilities do not suffer any more incidents of depression, alcoholism, or mental illness than do mothers without developmental disabilities (Tymchuk, 1990).

Systemic Conditions: The Social, Economic and Educational Environment

For 300,000 Canadians, to be branded with the stigma of a developmental disability is to be reminded daily that society rejects their claim to legitimate membership. One of the areas where this rejection is most evident is in the arena of employment. Less than three percent of the adult developmentally disabled population in Canada have competitive jobs, that is, are employed in the production of goods or services for which they receive at least the minimum wage. There is no outcry about this because the belief is that "the mentally retarded" are not only unable to make important decisions for themselves, meet the responsibilities of adulthood/parenthood, but are also unable to hold down real jobs. The knowledge of poor employment prospects only reinforces a deeply rooted sense of inferiority and failure (Kendrick, 1994). The attainment of a "regular job"—the most important symbol of having "made it" in the community-- is forever out of reach and they believe this is for reasons largely due to their own shortcomings.

Poverty

Families living in poverty are unable to thrive and are subject to widespread systemic discrimination where they are often denied housing and access to services and education. Lower education levels lead to lower paying jobs and ultimately, dependence on social assistance (Reitsma-Street & Engleder, 2000). Margaret and Mary both live with the effects of poverty everyday, but in varying degrees. Margaret has a car, lives in a subsidized three-bedroom housing unit, and participates in activities familiar to those in the dominant culture (e.g., camping trips, Cubs and Girl Guide groups, trips to Costco, etc). As a result however, Margaret and her family are often in debt. Mary on the other hand, has never had any of the material possessions that Margaret has, nor has she been in the same circumstances or made the same choices to incur the kinds of debts that Margaret has. When Mary decides to spend money not budgeted for, (e.g., on pizza), she goes without the bare necessities for a few days or week, but not usually longer than that.

Women in general tend to experience lower economic status than their male counterparts; they receive less pay for the same job and are affected financially due to single motherhood (Flax, 1987). Too often women living in poverty are marginalized to the point of invisibility. Women who are poor *and* who have a developmental disability live with a double cloak of invisibility. Both Mary and Margaret have experienced long term poverty and are likely to continue to do so because the options to seek further education, move up the career ladder, or pursue increased wages, are unlikely scenario's. This may be one of the areas where poor women of average intelligence and those with developmental disabilities, differ. Women who are living in poverty but do not have a developmental disability, may have more options available to them to raise their standards of living. These women are more likely to have better problem solving abilities, better skills to access resource information, and more effective time management skills than women with developmental disabilities.

The consequences of the sociopolitical events leading up to and following the last two economic recessions include disproportionate suffering for families living in poverty. These families are the first to have their limited existing services reduced during economic downturns, and the last to receive or to have services reinstated when circumstances improve (Miringoff, Miringoff & Opdyccke, 1996). They do not have a political voice and when they do, it does not carry great weight. Reliable funding for literacy training is a recent example of programs given low priority by governments, despite the fact that it is a pervasive issue in many individual's lives, including Margaret and Mary.

Literacy

Literacy is more than a set of mechanical skills "... the practices of reading and writing are inextricably bound within specific uses by particular actors from their different positions in the social order" (Weinstein, 1984, p. 480). Darville asserts that literacy is embedded in "social organization," and defined as "...the things that people do, their social practices; the relations among people brought into being by those practices, and through which their understandings and actions are concerted" (1989, p.1). Developing literacy empowers one's social organization; it provides a way that people can “name their world,” give voice to the realities of their lives, gain some distance from those realities, and then reflect upon them.

Margaret and Mary call it “a reading problem,” but it is more than that. It is not just a vehicle for following simple instructions on how to make a cake, or to read a bedtime story to a child-- literacy opens up a world of information that may be difficult to access otherwise. Parents who are literate have the ability to research current strategies in numerous books in order to learn ways in which to deal with difficult developmental stages. The participants on the other hand, have had to rely on their family members or various professionals where they receive often conflicting ideas on how to deal with their children's behavior as they go through the 'terrible two's or adolescent stages. The influence of family history is stronger in families who experience illiteracy because they have to rely on parental advice and their own memories, perhaps perpetuating poor techniques.

Reading is like food: it is sustenance. We use literacy to experience the world outside of our own so that we can learn things we may not be able to learn anywhere else. It shapes our views of the world around us, adds to our learning and social experiences, and enhances our fantasy world (Darville, 1989). If left only with people’s verbal tales, many individuals-- including mothers with developmental disabilities--are excluded or removed from much of the real world, and must therefore count on media contrived representations of what “social organization” supposedly looks like.

It seems more acceptable for individuals for whom English is a second language and not able to read in English, than it is for those with developmental disabilities to be illiterate in their own language. A mother who cannot read or help her children with their homework using English as her second language, would not likely have her parenting skills scrutinized and judged to the same extent as, for example, a mother with a grade two reading level. Margaret's ability to obtain her drivers license without being able to read, may be surprising initially to many of us, myself included, yet we would probably not question the fact that many people who immigrate to Canada, and for whom English is a second language, are customarily permitted to drive. Translation services are available to immigrants, but help with reading and writing is not as readily available to those with developmental disabilities. The implications of being unable to read and write English have the potential to reach into many other aspects of the lives of women with developmental disabilities, in a way that may not happen for a woman from a different culture who is unable to read or write English.

It appears that Margaret and Mary see poverty and their own illiteracy as barriers that are virtually impossible to overcome, ("A Reading Problem," "Consumerism on a Poverty Line Income," "Once in a Blue Moon"). While they recognize that not being able to read has been difficult, we do not know how much their reading levels could be improved given the existence of their developmental disabilities. It is only in the last decade that the school system has focused on maximizing the learning for students with developmental disabilities, making it highly probable that the effort to teach Mary and Margaret to read as children was not expended due to low expectations given their developmental disability.

The Same Goals, The Same Dreams, And The Same Disappointments

In spite of the strength of the issues associated with poverty and illiteracy-these two mothers still hold and ascribe to the same goals, dreams, and disappointments as mothers in the dominant culture. Mary dreams of leaving her apartment to live in a nice little house where she could buy clothes (and food) whenever she felt like it. Margaret would have ample respite and support to help her with Dane's special needs and would go on holidays with her family a few times a year.

While there is a tendency for the dominant culture to generalize about individuals with developmental disabilities, there are many parents who are of average intelligence who do not always meet the needs of their children in the best possible way. Great parents are the exception, not the norm. Not all parents excel in parenting, by consistently putting the best interests of the child first, providing healthy and positive learning experiences, properly feeding or providing all the material advantages (e.g. a nice home, turkey dinners, trips to Disneyland…). Nevertheless, based on my observations of the families I have worked with, the friends that I have, and the reading that I have done, the average parent tries to do the best with what they have emotionally, physically and cognitively.

Research has demonstrated that a healthy developmental outcome is more likely for children who remain in the care of their parents than for those placed outside of the family (Hooyman & Goyea, 1995; Walker, 1989). There are of course, exceptions to the rule. Parents (with or without developmental disabilities) who are not cognizance of their skill deficits and/or are unwilling to change, may be found to be inadequate parents. Issues such as drug addiction, mental illness, age, or ongoing family violence may limit a parent's capacity to improve their parenting skills or lifestyle due to choices they make. Women with developmental disabilities are often responsive and willing to participate with specialized parenting programs, and are often successful in their efforts to improve their parenting skills (Espe-Sherwindt, 1993; Feldman, 1986; Llwelleyn, 1999; Tymchuk, 1990). As with women in the dominant culture, the motivation to learn and demonstrate a change in parenting skill is more important. It is possible that if the barriers of poverty, isolation and illiteracy were removed, parenting would be a simpler process for Mary and Margaret. They would improve their capacity to learn the essential skills and reach outside of their family and personal support system.

Implications

As discussed in the "Limitations of the Study" section in Chapter Three, this study's sample came from an organization that supports individuals with developmental disabilities. Other parents with developmental disabilities may have different perspectives. It is important to understand that the small sample presented here cannot and should not allow for generalization of the results to the population of parents with developmental disabilities. The experiences of the two participants will differ from other mothers with developmental disabilities, just as the experiences of any two mothers will differ.

There are however, implications of the findings discussed above for programs and policies relating to services for parents with developmental disabilities. These implications are as follows:

1. In the Canadian context, the proclamation in the United Nations Declaration for the Rights of the Child states that every child has a right to have his or her basic needs met. This means that all governments must ensure adequate income in order to provide the social supports that are necessary for people to achieve a decent standard of living (National Council of Welfare, 1999). We need systemic solutions that work to erradicate

poverty, and acknowledge that it exists. Systemic solutions that offer guaranteed income and include access to quality health care, transit, housing and education (including homework support for parents, field trip subsidies, nutritious lunches for children). There needs to be the assurance that other necessary services (e.g. literacy classes) are available to anyone who requires them (Reitsma-Street et al, 2000). However, as government decreases its role in service provision we may need to look at different ways to fight poverty that involve the community. For example, Mary's life would benefit from more accessible food banks; ones that do not require long waits in lineups, and what she described as unsolicited, difficult interactions with people with whom she is uncomfortable with. Margaret will continue to require increased respite as the needs of her son take their toll on the family.

2. I have found that a large percentage of my work with families with developmental disabilities requires walking them through a maze of appointments, forms, locations, lingo, and increasing 21st century technology (e.g. debit cards, voice mail, etc.). Once we get through this, the business of parenting is relatively easy! Children and families have a right to integrated programs that reduce the frustrations that come with bureaucracies and "red tape." Social support policies must be created in ways that respond to the needs of all the members of the family and ensure the best possible outcomes for all members of the family.

3. While I do not advocate that every person should have children, irregardless of whether they have a disability or not, I do believe that we all deserve the right to choose. Given the variability of care provided by all parents, a definition or criterion should describe what constitutes adequate parenting. In addition to Campion's list of what the

dominant culture's "actual" parenting skills are, my definition of adequate parenting would ensure that middleclass values are not the gauge and that one's social context is taken into account when planning intervention. Both Mary and Margaret saw themselves as good parents even though Margaret was more likely to access the support of resources that were available to her and was more involved with her community. From my limited interactions with the participants, both clearly showed that it was important to them that they did things the "right" way in terms of parenting. This study did not attempt to go into any detail to assess the quality of parenting from the researcher's perspective. All the accounts were anecdotal and came from two women reflecting on their parenting styles and beliefs. Based on the information that was provided, both mothers made clear and consistent statements about their belief system around parenting roles; statements that I thought were consistent with mothers everywhere.

4. It would have been useful for Mary and Margaret as adolescents to have had practical information around decision making, birth control, socializing, positive role models and stable home lives (ie not moving constantly, living within their means, etc.). It is possible that these kinds of interventions could have prevented their unplanned pregnancies, low self-esteem and disconnect from the dominant culture. This theory is further corroborated by Margaret's statement about what she feels would have benefited her more in school than what she was actually taught: "Social skills, like being out there a little more in the community. And like learning how to balance a cheque book and housework, because I didn't get that at home from my mom or dad. I had to learn all that stuff on my own."

5. Everyone learns somewhere--formally or informally. In universities, people learn through studies. In businesses and bureaucracies, people learn by reports. In communities, people learn by stories. These community stories allow people to reach back into their common history and their individual experience for knowledge about truth and direction for the future. Despite the undeniable fact that many people have developmental disabilities, and that this is a social and cultural phenomenon, the social and cultural sciences have paid it scant heed. Parents with developmental disabilities have stories to tell but are not given much voice or legitimacy in the literature or their communities. Forums for parents to describe the services they do and do not need should include oral discussion panels and interviews with trained people to facilitate communication skills as a way in which to 'gleen' the stories from these parents. These strategies are consistent with the ways of knowing that are practiced by those with developmental disabilities. Peer and professional supports that increase self confidence, self esteem, parenting and socialization skills are necessary. It is important that organizations have an understanding of women's, (mother's), experience of self-definition in order to enhance our ability to promote health in women (Hartrick, 1996). Policy makers require more information in the generation of public policy relating to families with developmental disabilities (Nye and McDonald, 1979). Through further study of developmentally disabled parents and their children, we could get more answers as to whether these parents could be doing something differently than the non-disabled parent, in order to facilitate better outcomes in their children. Such studies must be designed in ways that evidence the tenets of inclusivity, (i.e. Social Role Valorization tenets) so that parents with developmental disabilities can become more a part of the

dominant culture of parenting. Research into effective procedures lags behind service needs and effective policies lag even further behind. Families continue to be adversely affected. (Tymchuk & Andron, 1992). Therefore, reliable answers as to how parenting programs can better support these families are essential. Further research should assess:

(a) resources available within the geographical community;
(b) the quality and applicability of service delivery;
(c) client surveys to determine what would best support these families in their daily family lives;
(d) the effects of poverty and illiteracy within this population;
(e) the identification of systemic change needed in areas such as affordable housing, access to education, increased vocational opportunities and a higher minimum wage.

Summary

As noted throughout this report, the factors that influence parenting in general are not just IQ, but rather one's capacity to understand and anticipate social events, to assess the consequences of personal actions, and to organize and plan household management and childcare. Healthy self-esteem, an internal locus of control, good problem-solving abilities and an understanding of what it means to be a parent are also very important (Campion, 1995; Espe-Scherwindt & Crable, 1993; Ray, Rubenstein & Russo, 1994; Rutter, 1983; Tymchuk & Andron, 1992). It is evident that although many of Mary and Margaret's parenting experiences are similar to mothers who are not developmentally disabled, IQ is still the main focal point in judging one's ability to parent when a parent has a developmental disability. It is important to realize that people with developmental disabilities are more similar than they are different to the dominant culture: they require affordable housing, good education, access to supportive resources and acceptance.

The term "critical mass" refers to the idea that a certain number of people are needed before the group and their needs become noticeable. "Since parents with developmental disabilities are an emerging population, critical mass status has not been attained, nor do these parents want to be singled out" (Tymchuk & Andron, 1992, p.31). Although this stance is understandable, it may work against them as supports and services continue to be "... uneven across localities, easily disrupted and seldom suitably matched to familial needs" (Tymchuk & Andron, 1992, p.31).

With the deinstutionalization process firmly a part of history, people with developmental disabilities are being raised from infancy within their own communities and usually within their own families. As the changing face of family evolves before our eyes, we as a society must continue to provide environment and opportunities that allow marginalized groups to experience the richness of their existence. Not only do governments bear a responsibility in this happening, but also community members, researchers, and the practitioners who support parents and their families. By pursuing strategies that address increased educational and economic opportunities, as well as by ensuring the true collaboration of the families affected by these policies, we are creating the building blocks of change.

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Appendix A

RECRUITMENT SCRIPT

Counsellor: I am here to tell you about a study that Kelly Fells, VACL's Parent Support Program staff, is about to begin for the completion of her Masters of Arts degree at the University of Victoria.

Before I begin, it is important for you to know that if you should decide not to participate in this study, it will in no way affect your eligibility for services with VACL or Kardel Consulting. You should not feel at all badly if you find that time constraints or any other personal reasons cause you to say no to being involved.

Kelly will be talking with two parents who have developmental disabilities. She will ask some questions about the participants' personal history but she is mostly interested in the participant's views on their roles as parent's. There are no wrong answers in this study. Kelly is just interested in your opinion about parenting.

There will be two interviews in total with each one not lasting more than ninety minutes. (But more likely sixty minutes for each interview.) There may also be a few follow up questions done by phone. The total time on this project shouldn't be more than three hours, done over a 4 week period.

During the interviews, Kelly will use a tape recorder and may take some notes. The participants will be able to read the thesis once it is completed if they like. Confidentiality will be kept by not using real names in the thesis or on the tapes. The tapes will be destroyed after the study is over. The typed interview will be kept in a locked cabinet for up to five years after the study is completed.

The participant can decide to stop participating at any time during the study or can choose not to answer a particular question(s).

Do you have any questions about this study? Do you have any concerns? *(If the prospective participants do not have any questions or concerns, the counsellor will then ask the prospective participants to tell her what her understanding is of what the study is about, the procedures and the rights they have around involvement. If the responses indicate a clear understanding of all this, the counsellor will then proceed by asking if they would like to meet with the researcher.*

Appendix B

LETTER OF CONSENT

TITLE OF PROJECT: Parenting Roles: From the Perspective of the Developmentally Disabled Parent.

INVESTIGATOR: Kelly Fells, Graduate Student 477-7231 ext 31/744-3021

SUPERVISORS: Dr. Carol Stuart, School of Child and Youth Care, Ryerson University: contact number 721-7979

Dr. Frances Ricks, School of Child and Youth Care, University of Victoria: 721-7989

DESCRIPTION AND PURPOSES OF THE PROJECT:

I, ____________________, understand that I am participating in a research project conducted by Kelly Fells for the completion of her Masters of Arts degree at the University of Victoria. This research project intends to look at how some parents with developmental disabilities understand their parenting roles.

Through interviews, I will be asked for some information about my personal history, and in addition, questions that will help the investigator (Kelly Fells) understand the experiences of families headed by parents with developmental disabilities. I may be asked to participate in two interviews: each of which will not be longer than ninety minutes. The total time spent with Kelly should not take more than three hours of my time and it will be done over a four week time period. Ms. Fells has said that she will provide daycare costs if the interviews take place when my child is not in school, and that we will meet somewhere private. I understand that Kelly will take notes as well as tape record the interviews we do together. If anything upsets me during the interview(s), I know that I will be allowed time to talk about that with Kelly or, if I need further support, I also know that I can talk things over with my counsellor at Kardel Consulting.

I understand that should I choose not to participate in this study, my decision will not affect my ability to obtain services from VACL or Kardel, now or in the future. I also understand that should I decide to participate, I can quit at any time during the study, and/or I can refuse to answer any questions I do not wish to answer. I am also encouraged to ask questions if I don't understand. Further, I know that my identity will be protected and that my real name will not appear on any of the written material. Anonymity will be protected by not using names and that identifying information will not be revealed but sections of the interviews may be quoted in the write-up of the research. Taped interviews will be erased immediately after responses have been coded in written form. The typed interviews will be kept on a computer disk for a period of five years and will be stored in a locked cabinet until they are destroyed. If I decide to terminate my involvement before the project is completed, I can choose whether the information collected to date may be used in Kelly's research project. I will have access to a copy of the thesis once it is completed and I will be invited to meet with Kelly to talk about the outcome of her study.

______________________________ ______________________________

Signature of participant Researcher

Date:______________________

Appendix C

AUTHORIZATION AND WAIVER OF CONFIDENTIALITY

I, ______________________________________, am providing authorization for you to release any and all information regarding my personal file, records and assessments including that deemed confidential, as requested by:

Kelly Fells who is doing her Master's thesis at the University of Victoria.

This authorization is only effective from November 1999, until August of 2000.

Signed: ________________________________

Date: __________________________

VITA

Surname: Fells Given Name: Kelly Ann

Place of Birth: Vancouver, British Columbia, Canada

Educational Institutions Attended:

University of Victoria	1985 to 2000
Camosun College	1979 to 1981

Degrees Awarded:

B.A.	University of Victoria	1989

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Title of Thesis:

Perspectives of Mothers with Developmental Disabilities: The Same Dreams, The Same Goals, The Same Disappointments

Author [redacted]

Kelly A. Fells

September 14, 2000