Mothers with Intellectual disability from Ethnocultural Communities in Canada:

A Narrative Study

by

Laura Pacheco

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ABSTRACT

The scientific study of parents and parenting with intellectual disability dates back almost one hundred years. Yet very little is known about the experiences of mothers with intellectual disability from ethnocultural communities, or the way in which culture shapes and constrains these women's lives (International Association for the Scientific Study of Intellectual Disability Special Interest Research Group on Parents and Parenting with intellectual disability, 2008). To shed some light on the experiences of mothers with intellectual disabilities from ethnocultural communities in Canada I undertook a narrative study underpinned by Collins' (1990, 2000) intersectionality theory. My study involved eight mothers with intellectual disability from different ethnocultural communities in Quebec and Alberta, Canada. I conducted between three and seven in-depth interviews with each mother over a period of two years, and spent time with these mothers as they went about their everyday lives.

The eight mothers that participated in this study came from different ethnocultural communities and identified as Aboriginal, Portuguese, Indian, Chinese, 'Trini-Indian' and Polish. The mothers had children ranging from five to twenty-one years old and five of the mothers cared for their children on a daily basis. The other mothers had regular visits with their children. At the time of the study, three of the mothers were married to the father of their children, one mother was living with her partner and the other mothers were divorced and single.

The life histories of the women who took part in this study were 'pot-marked' by experiences of loss and oppression. They experienced the loss of important people in their lives including family members and their children, experienced abuse as children and as adults and were isolated from their family and cultural community when they did not 'measure up'. Yet, woven into the narratives of these eight women are threads of love and resilience. The love they had for their children and their tireless quest to have them with them gave these women a purpose and instilled greater hope in their lives.

The women's narratives reveal that oppression they experienced *and* the resilience they displayed are rooted in 'culture': For these women, culture was 'a two-edged sword'. On the one hand, the lives of the eight women (including the choices that were available to them) were constrained by cultural expectations, for example, of the role of women. Moreover, when these women failed to perform their roles—as women, wives and mothers—according ‘to script’ (i.e., cultural expectation), they were punished: socially, psychologically, and in some cases, physically. On the other hand, the women acquired a more positive social identity, when they first became wives and mothers, as they were doing what was expected of them as women in their cultural community.

Each of the women who took part in this study were committed, above all, to being ‘good mothers’. And for these women, being a good mother sometimes meant having to flout other cultural expectations: It was not always possible to be all things to all people simultaneously (e.g., a good women, wife and mother). For example, to protect their children from abuse, some of the women openly contemplated divorce, even though this was frowned upon. Others came to accept that their children may be better off in the care of a foster family in order to give them a better life. These women often did what they thought was right for their children even at great personal cost, in terms of their own personal safety and exclusion from family and community relationships.

By sharing their life stories, these women contributed to a collective narrative that is based on experiences and reflective self-understanding; how they want to be seen and treated within their social world. The study findings have implications for policies, professional practice and research. Recommendations for future research studies include exploring the impact of culture on the interpretation of disability, the support provided and received by mothers with intellectual disabilities from ethnocultural communities and their families, exploring social class and strategies of resistance in face of poverty and investigating the experience of abuse in the lives of mothers with intellectual disability from ethnocultural communities.

Keywords: mothers, mothering, intellectual disability, ethnocultural community, oppression, resistance, narrative inquiry, intersectionality theory.

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CHAPTER 1. INTRODUCTION AND OVERVIEW

I want to begin by sharing the story behind the stories that are documented in this dissertation. I want to begin with this story as it sheds some light on why I was interested in documenting the stories of the women who took part in this study.

My first internship as a social worker was at a community organization for persons with intellectual disability. One of my first clients was a young woman, who I will call Nina. Nina was 25 years of age and she had a mild intellectual disability. She was a permanent resident from Ethiopia. Nina was three months pregnant with her first child when my supervisor assigned her to me at intake. My supervisor highlighted the fact that she had an intellectual disability *and she was pregnant*. Amongst other recommendations, my supervisor asked me to broach the topic of abortion with her. I didn't ask why.

My supervisor also suggested that I call Nina's social worker from the community health clinic, who had been working with her for over one year, to gain more of an understanding of 'the case'. I did so. This worker had only negative things to say about Nina's abilities and her potential as a mother: she expressed the view that Nina couldn't possibly take care of a child because she was like a child herself and was likely to regard her child as a doll. I got off the phone and I felt deeply uncomfortable.

I met Nina about one week later. Nina is a slim and shy woman, and she looked down at the ground for the first few minutes of our conversation. I congratulated her on her pregnancy. She responded with a smile. It was one of the only smiles she gave me during our one-hour meeting together. I asked her how she was feeling. Nina expressed excitement about having her first child with her boyfriend of a year and a half. I asked Nina how her family felt about her pregnancy. Nina seemed surprised by my question and said that her mother was happy; Nina was the youngest of four children and it was her turn to have a child. Nina then said "Dans ma culture, une femme c'est fait pour avoir des enfants": "In my culture, a woman is created to have children".

It struck me, that day and years later, that Nina received conflicting messages about her role and worth as a woman and mother from representatives (or heralds) of the majority culture (e.g., my supervisor and her social worker), and from her family and cultural community. I wondered if Nina's story was just 'her story' or if it represented the shared experiences of mothers with intellectual disability from ethnocultural communities in Canada. I turned to the literature in the field but could not find any answers to this question.

1.1 Why should we pay attention to these stories?

Until quite recently, the voices of mothers with intellectual disability have been muted within society, overshadowed by a grand narrative of incompetence (Roets, Reinaart & Van Hove, 2008). This grand narrative depicts mothers with intellectual disability as passive, dependent (i.e., never fully adults), and incapable of raising children (Booth & Booth, 1994; Sigurjónsdóttir & Traustadóttir, 2000). Set against this grand narrative are data from decades of research revealing that, while some mothers with intellectual disability struggle, many others succeed (Booth & Booth, 1994; Strike & McConnell, 2002; Llewellyn et al, 2010).

To date, most of the research in the field of parents and parenting with intellectual disability has been analytical-quantitative. However, over the last two decades an increasing number of studies have employed interpretive methods to investigate mothers', and to a lesser extent fathers' experiences (Booth & Booth 1994, 1995, 2000, 2005; Llewellyn, 1997; Llewellyn & McConnell, 2005; Mayes & Llewellyn, 2012; Mayes, Llewellyn & McConnell, 2005, 2008; Roets, Reinaart & Van Hove, 2008; Tarleton & Ward, 2007; Traustadóttir & Sigurjónsdóttir, 2008; Sigurjónsdóttir & Traustadóttir, 2010). Booth and Booth (1994) paved the way with their seminal study of the experiences of mothers and fathers with intellectual disability, informatively titled "Parenting under pressure".

Interpretive research has given voice to mothers with intellectual disability and generated rich insight into their lives and social realities. Studies have explored an array of topics including but not limited to parent reflections on their own upbringing (Llewellyn & McConnell, 2010); the phenomenon of becoming a mother (Mayes, Llewellyn & McConnell, 2006, 2008; Roets, Reinaart & Van Hove, 2008); the role of informal learning (Llewellyn, 1995); social support and community engagement (Booth & Booth, 1994, 1995, 2000; Guinea, 2000; Llewellyn & McConnell, 2005; Roets, Reinaart & Van Hove, 2008); and, the experience and aftermath of child welfare interventions

(Booth & Booth 2000, 2005; Mayes & Llewellyn, 2012; McConnell & Sigurjónsdóttir, 2010).

Research in the field of parents and parenting with intellectual disability however, has focused almost exclusively on the experiences of parents who are members of the majority culture (IASSID, 2008; Johnson & Traustadóttir, 2000). The experience of mothers from ethnocultural communities, and the influence culture has in shaping their experience and identity remains a major gap in knowledge. The International Association for the Scientific Study of Intellectual Disability (IASSID) Special Interest Research Group on Parents and Parenting with intellectual disability (2008) has identified this knowledge-gap as requiring "urgent and dedicated attention" (p. 5).

To begin addressing this gap in knowledge, I undertook a narrative study inspired by Booth and Booth's (1994) seminal work. My study involved eight mothers with intellectual disability from different ethnocultural communities in Quebec and Alberta, Canada. I conducted between three and seven interviews with each mother over a period of two years. In addition, I spent time with some of the participants and their families as they went about their daily routine (e.g., grocery shopping) in order to gain deeper insight into what their everyday lives were like.

The broad aim of the study was to shed light on the experience of mothers with intellectual disability from ethnocultural communities in Canada. For the purposes of this study, an ethnocultural community is defined as one that has an ethnic or cultural heritage that is not British or French and includes members from Native communities. People from the same ethnocultural community usually share a common ancestry, country of origin, language, and cultural traditions and includes communities that self-identify as being from an ethnocultural community (Canadian Ethnocultural Council, 2004) (Informed by Collins' (1990, 2000) intersectionality theory, I explored the role that culture (e.g., what it means to be a 'good' woman, wife and mother) has played in shaping the women's experience and self-understanding. Further, I explored agency in the women's lives, that is, how these women resisted oppression, and wrested 'authorship' of their own life stories.

1.2 What the study contributes

This study contributes to the field in three ways. First, this study provides understanding of the everyday experiences of mothers with intellectual disability from ethnocultural communities. The mothers' narratives illustrate the way in which these women grew up and how they have carried out their daily lives with their children and families. It revealed what was most important in their lives, including their family and cultural traditions, the significant events that shaped their lives (e.g., getting married, having children, getting divorced), their interactions with their loved ones and authority figures, and how they dealt with loss and abuse at different times in their lives.

Second, this study explores the interactions between intersecting social identities (i.e., mother+ intellectual disability+ culture) and larger social structures. More specifically, how culture (their family, ethnocultural community and societal ideals) can shape these women's experiences, and can impact self-understanding. Put differently, "the individual stories in all their uniqueness can be used to illuminate the human condition" (Booth & Booth, 2006, p.94). All too often, the women in the study received messages and guidance from others that conflicted with their beliefs, values and goals. Examples include but are not limited to being told they were "stupid", and being urged to have an abortion. The women did not however passively accept such messages or guidance: they did not always allow others to define them, or to make major life decisions for them. Rather, and in some cases, at great personal cost (e.g., personal safety, social exclusion), the women *resisted*. Asserting themselves as the authors of their own unfolding life stories, these women challenge the pervasive social stereotype of women with intellectual disability as passive and dependent. These women, in different ways and within different situations, used strategies of resistance when they faced oppression.

Third, by sharing and telling their stories, these women were able to contribute to a collective narrative that is based on their own experiences rather than on the perceptions of those in authority or members of the majority culture. These women were able to re-write their stories and those of their children to include how they wanted to been seen and treated within their social world. Their stories, as Connor

(2006) asserts contributes to knowledge as " … (b)y doing research with those labeled as "others" –with the specific desire to use their own words to represent themselves—enables the co-construction of knowledge".

1.3 How this thesis is organised

This thesis is divided into six chapters. The first chapter (after this introduction) describes what we know about parents and parenting with intellectual disability and explores the four waves of research in this field. The second chapter explores the theory (intersectionality theory) and how I went about doing the research (method). The third chapter includes the individual narratives of the mothers in this study. The fourth chapter highlights the common threads that run across the narratives and what we have learned from these women's narratives through an intersectionality theory lens. The final chapter highlights how this research might contribute to knowledge, possible strategies for change and my reflections as a student researcher.

CHAPTER 2. BACKGROUND

Research in the field of parents and parenting with intellectual disability can be traced back to the mid twentieth century. The literature now includes in excess of 400 published empirical studies (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). The earliest studies in the field addressed the question of heritability. These studies found that, although general intelligence is approximately 50% heritable, most children of parents with intellectual disability have 'normal' intelligence (e.g., Ainsworth, Wagner & Strauss, 1945; Brandon, 1957; Mickelson, 1947; Penrose, 1938; Reed & Reed, 1965). From the 1940s onwards researchers turned their attention to the question of competence. This research revealed, firstly, that parents with intellectual disability are heterogeneous with respect to parenting skills, and secondly, that they can learn parenting skills when teaching methods are matched to their learning needs (e.g., Budd & Greenspan, 1984; Feldman, 1994, 2010; Feldman Case & Sparks, 1994, 2000; Llewellyn, Traustadóttir, McConnell & Sigurjónsdóttir, 2010; Tymchuk & Feldman, 1991). In the 1980s, two other distinct but overlapping streams of research were initiated. One stream is concerned with identifying person-environment transactions that explain the observed variation in parenting and child outcomes (e.g., Mickelson, 1947; Aunos, Goupil & Feldman, 2008; Booth, Booth & McConnell, 2005; MacLean & Aunos, 2010; McConnell, Feldman, Aunos & Prasad, 2010). The other comprises qualitative studies, which have given voice to parents with intellectual disability and illuminated their first-hand experience (e.g., Booth & Booth, 1994, 2000; Llewellyn, 1995, 1997; Mayes, Llewellyn & McConnell, 2005, 2008; Traustadóttir & Sigurjónsdóttir, 2008; Sigurjónsdóttir & Traustadóttir, 2010).

Significant advances in knowledge have been made in the field of parents and parenting with intellectual disability, however the knowledge-base is limited in a number of ways. One limitation is that most studies to date have been based on clinical samples of parents who may not be representative of all parents with intellectual disability who are bringing up children in the community (Llewellyn et al, 2010). Another limitation is that most studies to date have focused on parents with young children. Consequently, little is known about the experience or support needs of parents who have older children (Feldman & Aunos, 2010). A third limitation is that few studies have explored the role and perspective of fathers with intellectual disability: the literature on parents and parenting with intellectual disability is, for the most part, a literature about mothers and mothering with intellectual disability (Johnson & Traustadóttir, 2000; Llewellyn et al., 2010). A fourth limitation is that almost all of the research to date has been conducted in high income countries. There is a dearth of knowledge about the situation and experience of mothers and fathers with intellectual disability in low and middle income countries (IASSID, 2008). Moreover, within high income countries, the experience of mothers from ethnocultural communities has been almost entirely neglected: Research in the field could be aptly described as 'gender and culture blind' (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). It is this absence of knowledge about the experience of mothers with intellectual disability from ethnocultural communities that I set out to redress through my doctoral research.

2.1 The Question of Inheritance

In the mid twentieth century researchers focused their attention on the question of family transmission (i.e., genetic inheritance). This research was driven, at least in part, by the eugenic hypothesis that if persons with intellectual disability were permitted to procreate they would produce a large number of 'defective' offspring, tainting the human gene pool and creating an intolerable burden on society (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; McConnell et al., 2003; Tymchuk, 1990). Several studies put this hypothesis to the test. Contrary to expectations, the research results revealed that, on average, children born to persons with intellectual disability have higher intelligence quotients (IQs) than their parents, and most have IQ scores that fall within one standard deviation of the population mean (Brandon, 1957; Mickelson, 1947; Penrose, 1938; Reed & Reed, 1965).

Brandon (1957), for example, examined the intellectual and social status of 150 children born to 'certified mental defectives'. That is, children born to mothers with intellectual disability (mean IQ = 73.5) who were formerly institutionalized, for an average of 14 years, at the Fountain Hospital in London, England. Where the mother's mean IQ was 61.1 on the Terman-Merrill (range 38 to 84), 99 (91%) of the children were found to have intellectual quotients within the normal range. An important finding was that there were differences in the IQs of the children depending upon where they were raised. While the 30 children raised by their mothers in the institution had a mean IQ of 98.7, 25 raised in foster care had a mean IQ of 96.8, and 38 in orphanages had a mean IW of 87.6. The results indicated that only 3.7 % of the children born to these mothers with intellectual disability could be classified as "mentally defective".

In a similar study, Ainsworth, Wagner and Strauss (1945) examined the general behaviour and social maturation of 115 children (mean age of 98 months) born to 50 former residents (mean IQ = 68.2) of the Wayne County Training School in Detroit, Michigan, USA. Based on the mothers' reports, 94% of these children were rated as "fair" or "no problem" with respect to their behaviour. Further, employing the abbreviated version of Vineland Social Maturity Scale, the study found that 89% of the children were socially competent, developing at the same level or above the level of children of the same age.

Despite these empirical findings, in many parts of North America the eugenic policy and practice of involuntary sterilization continued, unabated, for decades. In Alberta, Canada, for instance, a total of 2832 children and adults were sterilized under the Sexual Sterilization Act, and this Act was not repealed until 1972 (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). In many countries, the involuntary sterilization of persons with intellectual disability continues even today (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008).

2.2 The Question of Competence

From the mid twentieth century onwards, the research pendulum swung from nature to nurture as researchers began to address the question of competence. Two questions dominated the field. The first was whether parents with intellectual disability could competently care for their children (Ainsworth et al., 1945; Booth & Booth, 1996; Dowdney & Skuse, 1993; Keltner, 1992 Mickelson, 1947; Tymchuk, 1990, 1992). The second was whether perceived parenting deficits could be remedied through training (Feldman et al., 1985; Feldman 1991, 1994, 1998, 2004, 2010; Feldman, Case & Sparks, 1992; Keltner et al., 1995; Llewellyn et al., 2003). A proliferation of studies revealed that parents with intellectual disability were diverse with respect to parenting competence and—with appropriate training and support—could learn basic child care, home safety and other parenting skills (Budd & Greenspan, 1984; Feldman, 1991, 1994, 2010; Llewellyn, 1990; Llewellyn et al. 2010; Tymchuk, 1992).

2.2.1 Measures of competence

In one of the earliest studies, Mickelson (1947) explored the link between characteristics of 'feeble-minded' mothers, including their IQ, and parenting and child outcomes. The study included 90 'feeble-minded' mothers who had a total of 300 children. Based on a review of agency records, Mickelson (1947) found that 40% of the mothers provided satisfactory care, 43% provided questionable care and 26% provided unsatisfactory care to their children. Of those mothers who were classified as providing questionable or unsatisfactory care, the majority had low IQs in the range of 30-49. Further, the competence of these mothers was associated with a myriad of psychosocial variables. Other factors, including the mother's mental health, degree of harmony between the couple, number of children and poverty were found to be better predictors of parenting competence than maternal IQ. More than forty years later, Keltner (1992) compared a sample of 34 mothers with intellectual disability (mean IQ = 60.8) to a sample of 32 mothers without intellectual disability on a variety of measures. The study found that the mothers with intellectual disability perceived themselves as less competent, and had more difficulty with basic child care and parent-child interaction skills. However, the results also revealed substantial variability with respect to the abilities of the mothers with intellectual disability: many of the mothers provided a level of care comparable to the mothers without intellectual disability.

The parenting competence of persons with intellectual disability has also been explored in interpretive studies (Booth & Booth 1994, 1995, 1996, 2000). Booth and Booth (1996) drew upon Cathy and Len's story (taken from their larger 1994 narrative study) to illustrate the influence of the wider social network on the parenting abilities of persons with intellectual disability. The dramatic storylines within Cathy and Len's story are not unique to them, they represent many of the challenges that parents with intellectual disability face within our society including poverty, loss of a loved one, dealing with a child's behavioural issues, discrimination and the presence of child welfare in their lives. Based on this and other family stories, Booth and Booth (1996) observe that parenting competence is not solely determined by the parents' personal characteristics; children's characteristics (e.g., age, temperament, behaviours and presence of disability) and family resources including support available and parent satisfaction with this support¸ also influence parenting competence. In addition, Booth and Booth (1996) observed that any one parent could demonstrate strengths in some areas and limitations in others. A parent might, for example, demonstrate warmth and responsiveness, but have difficulty with boundary setting and discipline. Parenting competence is thus multi-faceted and can be impacted by different contexts and psychosocial factors.

2.2.2 Parent training studies

Since the 1980s, more than thirty studies have investigated the efficacy of parenting training programs for parents with intellectual disability (e.g., Feldman Case & Sparks, 1994, 2000; Llewellyn et al., 2003a, Tymchuk et al., 1988). These studies are diverse with respect to research design (e.g., single-case, true-experimental) and the behaviours targeted by training (e.g., basic child care, home safety, parent-child interaction). Yet these studies have produced a consistent trail of evidence showing that parents with intellectual disability can learn, adapt and overcome perceived parenting deficiencies when programs are individually-tailored, behaviour-based and delivered in-situ (Budd & Greenspan, 1985; Feldman, 1994; Llewellyn et al., 2003b; Tymchuk & Feldman, 1991; Wade et al., 2008).

Feldman, Case and Sparks (1992) conducted one of the first intervention studies. They conducted multiple home visits to assess the parenting skills of 22 mothers with intellectual disability and 12 'non-handicapped' mothers. The 22 mothers with intellectual disability were then randomly assigned to either a control group or behaviour-based training. The training consisted of weekly 60-90 minute in-home, behaviour based sessions that were tailored to each parent's learning needs. Post-testing revealed that the mothers who received the training attained a level of performance on each of the targeted skills comparable to the non-disabled mothers (Feldman 1994; Feldman Case & Sparks, 1992; Wade et al., 2008).

A decade later, Llewellyn, McConnell, Honey, Mayes and Russo (2003) investigated the efficacy of a behaviour-based, in-home parenting training program called Healthy and Safe. This flexible program, consisting of weekly 60-90 minute in-home sessions delivered over a period of 8 to 12 weeks, is designed to equip parents with intellectual disability with the skills they need to make their homes safer for young children, and respond appropriately to child illness and injury. A total of 45 parents with intellectual disability were randomly assigned to three groups, with each group receiving the program sequentially. With pretest, posttest and follow-up measures, the effect of the program was compared with two active 'control' conditions: pre-existing services and pre-existing services plus lesson booklets (i.e., self-instruction). By comparison with the control conditions, Healthy and Safe proved to be effective in improving the parents' ability to recognize home dangers and make their homes safer for their children and, in improving parent capacity to recognize and respond appropriately to symptoms of child illness or injury.

The now substantive body of evidence shows that parents with intellectual disability can learn parenting skills with appropriate support and behaviour based training strategies (McConnell et al., 2010). What remains unanswered, however, is how parents with older children, that is, children in late childhood and adolescence, can be effectively supported.

2.3 The Question of Context

From the 1980s onwards researchers have moved the field of parents and parenting with intellectual disability beyond parenting training. Increased research attention has focused on identifying person-environment factors that may explain the variability observed in parenting and child outcomes. Such factors include but are not limited to the parent's upbringing, exposure to poverty and prejudice, psychiatric morbidity, pregnancy and birth outcomes, and formal and informal social support (Aunos, Goupil & Feldman, 2008; Booth, Booth & McConnell, 2005; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; Keltner et al., 1999; MacLean & Aunos, 2010; McConnell, Feldman, Aunos & Prasad, 2010; McConnell et al., 2003; McGaw, Shaw & Beckley, 2007; Tymchuk, 1994). Furthermore, this stream of research has turned the spotlight onto systemic failures including, for example, the failure of services to address basic needs (e.g., for safe housing and health care) and/or to make reasonable accommodations.

2.3.1 Psychosocial risk

A focal point for the current generation of researchers is psychosocial risk. Several studies have, for example, determined that mothers with intellectual disability, tend to have small social networks and report low levels of social support (Feldman et al., 2002; Llewellyn, McConnell & Mayes, 2003; McGaw et al., 2007; McConnell et al., 2003; Stenfert- Kroese, Hussein, Clifford & Ahmed, 2002; Tymchuk, 1994). Further, studies have found that mothers with lower levels of social support tend to report higher levels of stress and more frequent or intense child behaviour problems (Feldman et al., 2002; Feldman et al., 1997; Stenfert- Kroese et al., 2002; Sterling, 1998).

Feldman, Varghese, Ramsay and Rajska (2002) examined the relationship between parenting stress, social support and mother-child interaction in 30 mothers with intellectual disability. They found that mothers with higher levels of social support reported lower levels of stress and more positive interactions with their children. Similarly, Sterling (1998) investigated the effect of parenting stress, satisfaction with social support and depression scores on parenting abilities. The findings of this study suggest that parents who are more depressed and more socially isolated may display poorer parenting abilities.

Other studies have investigated the influence of child removal on parent and child outcomes. For example, Aunos, Goupil and Feldman (2007) compared mothers with intellectual disability who do and do not have custody of their children across a number variables: family variables (age, number of children, income etc.), community involvement, support and services, physical and mental health, parents' adaptive behaviours and child behaviour problems. The study concluded that mothers with intellectual disability that have custody of their children tend to be more involved in the community, more satisfied with the services they receive, and have higher incomes than mothers who do not have custody of their children.

Several studies have found that mothers with intellectual disability, on average, suffer poor mental health and poor physical health, in comparison with their non-disabled peers (Feldman et al., 2002; Llewellyn, McConnell & Mayes, 2003; McGaw et al., 2007; McConnell et al., 2003; Tymchuk, 1994). Tymchuk (1994), for example, found that mothers with intellectual disability were approximately three times more likely than their non-disabled peers to report clinically significant symptoms of depression. More recently, Llewellyn et al., (2003) found that mothers with intellectual disability, reported significantly poorer levels of mental and physical health, compared with population norms for women of child-bearing age. In addition, McGaw et al., (2007) found that 45% of parents with intellectual disability reported symptoms of psychopathology, which exceeded the levels reported by the general population. The study also found significant relationships between the presence of psychopathology in these parents and mental disorders in their children.

The life stories of parents with intellectual disability have also shed light on the personal and social issues these parents face. Molly Austin's story, documented by Booth and Booth (1993), poignantly illustrates this point. Though Molly's story is her own, "it carries echoes of the experiences of other parents in this study" (Booth & Booth, 1993, p.13). Molly's story begins with her own dismal upbringing; her father abused her after her mother's passing and she experienced a number of foster placements. Molly had no positive parental role models. Molly fell in love with Kevin and early on in their relationship they started a family. From the beginning, Molly and her husband had little social support and her adjustment to her role as a mother was complicated by post-partum depression for which she received no professional support. The daily lives of Molly and her family were difficult at best as they struggled to make ends meet and keep their children safe and healthy in poor living conditions. One of the lessons to be learned from Molly's story can be gleaned from the research in this field at large. That is, parenting does not happen within a vacuum; families are surrounded by environments and cultures that can impede and or support their family life.

2.3.2 Systemic failures and discrimination

International studies have revealed that parents with intellectual disability are more likely to have their children removed by child welfare than other stigmatized groups, including parents with mental illness and/or drug and alcohol issues (Booth, Booth & McConnell 2005a, 2005b; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). Over-representation of these parents within the child welfare system is, at least in part, explained by "prejudicial and discriminatory treatment" (McConnell & Llewellyn, 1998, p.36), and systems that are professionally centered and ill-equipped to meet these parent's needs (Booth & Booth, 2005 a, 2005b; McConnell & Llewellyn, 2002; McConnell, Feldman, Aunos, & Prasad, 2010; McConnell & Sigurjónsdóttir, 2010).

McConnell, Feldman, Aunos and Prasad (2010) investigated prevalence and outcomes for children of parents with cognitive impairments involved in child maltreatment cases in Canada (excluding Quebec) by analyzing the Canadian Incidence Study of Reported Child Abuse and Neglect (CIS-2003). The findings showed that one in ten child maltreatment investigations involved a parent with a cognitive impairment. Further, more than one in four child welfare court action proceedings (with high probability of placement) involved a parent with a cognitive impairment. Neglect was noted as the most common child protection concern (48%), including physical neglect (21.3% of neglect cases) and "failure to supervise resulting in physical harm" (15.1% of neglect cases). Perceived parental non-cooperation was found to be the most potent predictor of child welfare court action in these cases. This study confirmed previous findings (Llewellyn et al., 2003; Booth et al., 2005a, 2005b) that children of parents with intellectual disability are disproportionately represented in the child welfare system, and are subject to more intrusive outcomes.

Another consistent finding within the literature is that the service system is ill-equipped to meet the needs of parents with intellectual disability (Booth & Booth, 1994, 1995, 2000; Tymchuk, 1990; Llewellyn, 1995, 1997; McConnell et al., 2010). Booth (2000) outlined key features of the service system that disempowered parents with intellectual disability. Firstly, the service system offers fragmented services. In other words, there are often many service providers involved in the lives of these families for a limited period of time. Further, there is usually little co-ordination or communication between systems and with the parents. Second, there is often a gap in services, where workers and systems lack knowledge of best practices to support parents with intellectual disability. Thirdly, the service system is crisis driven; the system only responds when there is a crisis as opposed to preventing issues such as personal and family deterioration. Similarly, Wade, Mildon, and Matthews (2007) identified professional centered practices, that is where professionals identify parents' needs as opposed to seeking or collaboratively setting goals with the parents, as a barrier to successful practice.

The different views of needed supports have been explored from both parent and professional perspectives (Llewellyn, 1995, 1997; Tarleton & Ward, 2007; Tucker & Johnson, 1989). A more thorough exploration of the insider's views of supports will be expanded upon in the next section, when I seek to further understand the experiences of these mothers. However, what is important to note here is that the supports and programs that have been developed and offered to these parents have primarily focused on parenting training and overlooked other perceived support needs (Booth, 2000; McConnell & Llewellyn, 2010). For example, MacLean and Aunos (2010) found that parents valued opportunities to get out of the house, participate in groups, share their experiences as mothers and connect with people other than their family.

2.4 The Question of Experience

A fourth wave of research has been concerned with giving voice to parents with intellectual disability and understanding the "the subjective realm of lived life", that is to find out what life is like for them (Booth & Booth, 1994, p. 23). This stream of research dates back to the 1980s and is therefore contemporaneous with other streams outlined above. Indeed, early interpretive studies helped to usher in research on the contextual determinants of parenting success by generating insight into the experience and social realities of parents with intellectual disability, including the many intrinsic and extrinsic factors shaping their experience (Booth, 1995; Booth & Booth, 1994, 2000; Llewellyn & McConnell, 2005; Mayes & Llewellyn, 2012; Mayes, Llewellyn & McConnell, 2005, 2008; Roets, Reinaart & Van Hove, 2008; Traustadóttir & Sigurjónsdóttir, 2008; Traustadóttir & Sigurjónsdóttir, 2010).

British researchers, Tim and Wendy Booth (1994), were among the first to employ interpretive methods to study the lives of parents with intellectual disability. In their ground-breaking study (1994), titled "Parenting under pressure", they explored the personal accounts of 33 mothers and fathers with intellectual disability living in South Yorkshire, England. The study produced a contextual understanding of the challenges and hardships these parents faced. Pushed to the fringe of society, many of the parents were struggling to create the life they wanted for themselves and for their children. They were struggling to 'live up' to their own and others' expectations in the face of poverty, and with little or no positive social support. Many of the parents felt like their parenting was constantly under the microscope, and they perceived that others, including their own families, were just waiting for them to fail. Woven through their stories was the ever-present fear of 'the welfare' coming to take their children away, a fear which all too often came to pass. More than half of the parents in the study reported having one or more children taken from them. Booth and Booth (1994) observed that the love these parents had for their children was unwavering as they clung on to their identity as parents and the hope that they would someday be re-united with them.

More recent studies on the lives of mothers with intellectual disability have expanded on the insights that were gleaned from Booth and Booth's (1994) seminal work. There are now more than twenty studies that have employed interpretive methods to explore and document the experiences and perspectives of parents with intellectual disability in Britain, the United States, Canada, Australia, New Zealand, Iceland, the Netherlands, Belgium and Sweden. Some studies have been cross-sectional (point-in-time), others longitudinal. Some studies have been broad in scope, while others have focused on specific life experiences and events, such as the experience of pregnancy and becoming a mother, and the experience of child welfare intervention and child removal (Booth & Booth, 1995; Mayes, Llewellyn & McConnell, 2006, 2008).

Across this broad spectrum of interpretive research, there are four over-arching themes. These are (1) the meaning of motherhood (Booth & Booth, 1994, 1995; Llewellyn, 1997; Mayes, Llewellyn & McConnell, 2006, 2008); (2) the role of informal learning and social support (Llewellyn, 1995, 1997; Tarleton & Ward, 2007; Tucker and Johnson, 1989; Mirfin-Veitch, 2010), (3) poverty and prejudice (Booth & Booth 1994, 2005; Llewellyn & McConnell, 2005; Mayes & Llewellyn, 2012); and, (4) Parenting agency/resistance (Mayes, Llewellyn & McConnell, 2006, 2008; Roets, Reinaart & Van Hove, 2008; Traustadóttir & Sigurjónsdóttir &, 2010). Although most interpretive research speaks of parents with intellectual disability, almost all of the studies focus exclusively on mothers (Llewellyn et al., 2010).

2.4.1 The meaning of motherhood

The importance that women with intellectual disability attribute to becoming and being a mother is a central theme within interpretative studies (Booth & Booth 1994, 1995; Llewellyn, 1997; Mayes, Llewellyn & McConnell, 2006, 2008; Mayes &

Sigurjónsdóttir, 2010). Becoming and being a mother represents a rite of passage for these women as they enter a valued social role (Booth & Booth 1994, 1995; Llewellyn, 1997; Mayes, Llewellyn & McConnell, 2006, 2008).

Becoming a mother was explored in Mayes, Llewellyn and McConnell's (2008) phenomenological study where they interviewed 17 expectant mothers with intellectual disability. In their study, the authors identified three phases of becoming a mother. The first phase was finding out that they were pregnant. This was when these women recognized the physical symptoms of being pregnant and experienced the positive emotions of having a baby growing inside of them. The second phase came to be when these women realized that their life would now be different; that their life would be centered around keeping themselves healthy for their un-born child. This was also when they began developing a relationship with their un-born child. The third phase was when these women began looking outward and thinking about who is around them and what kind of influence they could have in their baby's life. These women then began creating a social network that was based on people they believed would be a positive support to their baby and family.

2.4.2 The role of informal learning and social support

One recurring observation is that mothers with intellectual disability often have little or inadequate informal support (Booth & Booth 1994, 2000; Guinea, 2000; Llewellyn & McConnell, 2005; Tarleton & Ward, 2007). More specifically, support within their mothering role is sometimes non-existent (Booth & Booth 1994, 1995; Guinea, 2000), is not adapted to their learning needs (Booth & Booth 1994, 1995, 2000) or they do not feel the support provider wants them to succeed (Booth & Booth 1994, 1995, 2000; Llewellyn & McConnell, 2005; Tucker & Johnson, 1989). Mothers also want support beyond their parenting role such as emotional support (Booth & Booth, 1994, 1995; Guinea, 2000; Tarleton & Ward, 2007), support in understanding the system (Booth & Booth 2000, 2005; Tarleton & Ward, 2007) and support with environmental/practical issues including housing, debt and employment (Booth & Booth, 1994; Tarleton & Ward, 2007).

Llewellyn's (1995) in-depth, multi-year study involving six families headed by parents with intellectual disability was one of the first to highlight the role of informal social support. One important theme was that support was not one dimensional, in that the partners benefited for the most part from mutual support, where they gave and received support from each other in different areas of family life. Reciprocity was seen as most positive when their partner offered them emotional support along with the practical support in daily life. Support from family members was deemed most helpful when it was a ‘good fit’ with their own parenting practices and values. The parents also described how support was deemed un-helpful when the support provider ignored their own wishes or discounted their views. The parents in this study also indicated their preference in receiving support beginning with their partners, family members, and then professionals.

Similar insights are reported by Tucker and Johnson (1989) who conducted an ethnographic study involving 12 ‘mildly retarded mothers’. These investigators found that social support providers could be either competence promoting or competence inhibiting. Competence promoting support providers demonstrated unwavering belief in the mother’s capacity to care for her children, and worked to build the mother’s confidence in her own abilities. Mothers that received competence-promoting support became more competent in their mothering role. Competence inhibiting support providers, on the other hand, often belittled the mother, and gave her little opportunity to develop her parenting abilities by ‘doing for’ rather than with them.

The research also points to the importance of the wider social network, such as the community, in supporting mothers with intellectual disability (Booth & Booth 1994, 1995; Llewellyn 1997; Mayes, Llewellyn, & McConnell 2006, 2008). Brigit Mirfin-Veitch’s (2010) three- year longitudinal qualitative study investigated citizenship and social participation in the lives of parents with intellectual disability. In-depth interviews were carried out with 19 parents; 13 mothers, 6 fathers and members of the participants social network that were deemed to be providing ‘valuable assistance’. Parents that described being well integrated within their community described feeling more supported and having increased access to community resources. These parents also described more positive parenting experiences as compared to parents that were not well integrated within the community.

2.4.3 Experiencing Prejudice

Women with intellectual disability often face negative attitudes to wanting, becoming and being a mother (Booth & Booth 1994, 1995, 2000; Llewellyn, 1997; Llewellyn & McConnell, 2005; Mayes, Llewellyn & McConnell, 2005; Roets, Reinaart & Van Hove, 2008). As adolescents and young adults, persons with intellectual disability are often discouraged from forming intimate relationships and are not usually socialized towards parenthood (Booth & Booth, 1994, 1995). And should they conceive, many women with intellectual disability will be encouraged, if not coerced by people close to them to abort (Booth & Booth, 1994, 1995, 2000; Llewellyn & McConnell, 2005; Mayes, Llewellyn, & McConnell, 2005). Traditions and celebrations that are most often accorded to first time mothers are not usually experienced by mothers with intellectual disability. Instead, many face opposition from family, friends and the various systems around them (Booth & Booth 1994, 1995, 2000; Llewellyn, 1997; Llewellyn & McConnell, 2005; Mayes, Llewellyn & McConnell, 2005; Roets, Reinaart & Van Hove 2008).

One of the most common experiences among mothers with intellectual disability is of child welfare involvement: Many mothers live with an ever-present fear of ‘the welfare’ coming to take their children away (Booth & Booth, 1994, 1995, 2005; Booth, Booth, & McConnell, 2005; Llewellyn & McConnell, 2005; McConnell & Sigurjónsdóttir, 2010; Roets, Reinaart & Hove, 2008). Interpretive studies have consistently found that mothers with intellectual disability perceive that they are not given ‘a fair shot’ by child welfare authorities; they feel as though they are ‘fighting a losing battle’ (Booth & Booth, 2000). Many of these mothers report feeling as though their every move with their children was being watched, and as soon as they made a mistake, this was used against them (Booth & Booth, 1994, 2005; Llewellyn & McConnell, 2005). Many mothers with intellectual disability also describe feeling lost within the system as they are not given support in understanding their rights, the process or the outcome of the court decision (Booth & Booth, 1994, 2000, 2005; Llewellyn & McConnell, 2005). In addition, many mothers who have had a child or children taken from them are left to deal with their emotional pain with little support from their informal and formal social system. This is illustrated in the following quote “… She feels lost without them. She keeps saying that she has no life. She wishes she were dead” (Booth & Booth, 2000, p.30).

Up until recently, very little was known about how mothers with intellectual disability deal with the loss of a child through involuntary placement and the impact this has on their mothering identity. Mayes and Llewellyn's (2012) narrative study helped fill in this knowledge gap as they interviewed seven mothers with intellectual disability following the involuntary removal of their children. Their study revealed three storylines. In the first storyline the mothers described, "Living as the mother I am". These mothers, in time, accepted their children's placement and were able to maintain their mother identity, only in a different way. The second was "Living as the mother I should be". These mothers' narratives revealed that it was difficult to see their children being raised by another woman, as they felt this was a role that they should be filling. The third narrative thread was "Not feeling like a mother anymore". These mothers felt that their mothering role was taken away when their children went into placement as they had limited, if any, contact with their children. The authors conclude that mothers within their study "demonstrated grief that is ambiguous and ongoing" (Mayes & Llewellyn, 2012, p.23).

2.4.4 Maternal agency/resistance

The life stories of mothers with intellectual disability are not only about the struggles they face when interacting within their social world, but also about the ways in which they rise above prejudice and systemic barriers. In other words, their life stories reveal how they have exercised agency and resistance (Booth & Booth, 1994; Mayes et al., 2006; Traustadóttir & Sigurjónsdóttir, 2010; Roets et al., 2008). For example, Traustadóttir and Sigurjónsdóttir (2010) explored the strategies employed by parents with intellectual disability in their interactions with the service system. Overt and covert resistance strategies were uncovered in the experiences of these parents and included concealing their pregnancy from extended family and support system (as they wanted to raise their children); refusing to accept services (as they were aware of bias and or had a negative past experience); pretending to conform (in order to reduce the risk of child removal); establishing a parent group or becoming self-advocates; and, staying in the public eye as they were aware that resisting or hiding could increase the risk of child removal. The parents' stories also revealed differences in the way that fathers and mothers resisted the system. Fathers with intellectual disability tended to be more overt by actively resisting constraints, while, mothers covertly resisted, for example, by complying with services in order to ensure that they could keep their children with them.

Rosa's life story, documented by Roets et al., (2008), further illustrates the ways in which mothers with intellectual disability may resist oppression. Rosa is a single mother with intellectual disability raising two children in Belgium. Her story contains several themes. First, it revealed the tension between Rosa's stigmatized label as a mother with intellectual disability and the positive status of being a mother. Rosa's narrative pointed to the ways in which she was treated as a woman with intellectual disability and was made to feel "less than" by her informal and formal social network. Rosa consciously focused her energy on doing what she needed to do as the mother to her young children. The second theme was Rosa's battle against the dominant discourse in order to create a positive image of herself as a mother with intellectual disability. Within her life story, Rosa grappled with the ideas and stereotypes of who she was and ought to be. She discussed the words and conceptions that are associated with being a mother with intellectual disability and how she chose her own words and images to define herself. Thirdly, Rosa's life story illustrated the ways in which she exercised agency, by employing creative strategies, in order to keep her daughter with her. She agreed to the services that were offered and enlisted people that would help her advocate for her rights. The authors conclude that mothers with intellectual disability are often caught in power struggles, where their power is subverted, especially when dealing with the child welfare system.

When we review the life stories of mothers with intellectual disability we see how the larger socio-political context shapes their experiences (Booth & Booth 1994, 1995; Llewellyn & McConnell, 2005; Roets et al., 2008). Firstly, we see how dominant ideologies and social stereotypes impact the life experiences of these parents. We see how having intellectual disability means "… inhabiting landscapes that are pathologized and marginalized by impermeable label borders" (Roets, Reinaart, & Van Hove, 2008, p.105). These label borders are driven by pervasive stereotypes that tag persons with intellectual disability as 'childlike', 'sexually deviant', 'dependent' and incapable of learning (Booth & Booth, 1993; Llewellyn, McConnell & Ferronato, 2003). We also see how two unlikely social locations—being a person with intellectual disability and being a mother—collide and challenge the dominant discourse of both disability and mothering (Llewellyn & McConnell, 2005). Both of these social locations have been subject to scrutiny within society and seem to portray paradoxical positions; ‘the perfect mother’, as being completely responsible in meeting all of her children’s needs independently versus the person with intellectual disability who is perceived as dependent on others for support (Booth & Booth, 1994). By becoming mothers, women with intellectual disability face the stereotypes and ideals of their ‘dual identity’, as a mother with intellectual disability. This identity, once actualized, cannot be separated, but understood only as these two identities intersect within personal and systemic realms (Connors, 2000).

The ideologies that mothers with intellectual disability face are absorbed within society; it penetrates thinking and impacts everyday experiences. In other words, stereotypes and expectations of mothers with intellectual disability are internalized and if left unchallenged, can guide certain actions, such as child welfare interventions (Booth & Booth, 1994). Thus the scrutiny that these mothers face at the hands of child welfare can be partly explained by the internalization of stereotypes (Booth & Booth 1994, 1995, 2006; Llewellyn & McConnell, 2005). This ‘matrix’ of oppression illustrates how intersecting identities, such as motherhood and intellectual disability, are influenced by many social forces: stereotypes, ideologies, and power relations. This in turn impacts the everyday experiences of parents with intellectual disability and their interactions with their wider social milieu (Collins, 1990, 2000).

2.5 Research-Knowledge Gap

Interpretative research has given voice to parents with intellectual disability. However, significant gaps in knowledge remain (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; McConnell et al., 2010). The first is the lack of attention paid to the influence of gender on the experiences and support needs of mothers and fathers with intellectual disability in their role as parents (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; Llewellyn et al., 2010; Mayes & Sigurjónsdóttir, 2010). The second is that there is a lack of cultural diversity within the life stories of mothers with intellectual disability. More specifically, there is a lack of research exploring how culture shapes the experiences of mothers with intellectual disability (IASSID Special Interest

Research Group on Parents and Parenting with Intellectual Disability, 2008, Llewellyn et al., 2010; McConnell et al., 2010).

2.5.1 Gender and intellectual disability

To date, most interpretive research with parents with intellectual disability has focused on mothers with intellectual disability; little attention has been given to the different experiences of being a mother and being a father with intellectual disability. This implies that mothering and fathering are experienced in the same way and that gender specific roles and expectations do not impact experiences (Johnson & Traustadóttir, 2000; Llewellyn et al, 2010). More specifically, Mayes and Sigurjónsdóttir (2010, p.18) observe that “the genderless orientation of the literature means that the experiences of women as mothers have been absorbed in a discussion of parents and parenting, while the experiences of fathers have been largely ignored”.

Mayes and Sigurjónsdóttir’s (2010) paper is one of the only gender specific explorations of the transition to parenthood of men and women with intellectual disability (from pregnancy to having a baby). The researchers, who come from Australia and Iceland, used a gendered perspective to analyze their two doctorate studies. This research surfaced some important insights. The first was that the participants were fully engaged in becoming and being mothers and fathers and both faced opposition within their respective roles. Both the mothers and fathers prepared for parenthood, however, they focused on different aspects. The mothers tended to prepare their informal social network by rallying people around them that would be most helpful. The fathers on the other hand tried to locate people in the system (i.e. disability advocates, lawyers) to help them keep their children as they knew very well that they were being judged and watched. The support that was offered and given to the fathers and mothers after the birth of their children was also very different. Health care providers mainly focused their attention on the mother and child, leaving the fathers feeling like they were pushed aside and ignored. Mayes and Sigurjónsdóttir (2010, p.29) conclude that “Treating their needs as identical or neglecting the needs of one parent makes the transition to parenthood more difficult for women and men with intellectual disability as individuals, as a couple, and for the whole family”. A gendered perspective is important, as there are specific expectations of men and women based on particular social and cultural contexts.

2.5.2 Culture and parenting with intellectual disability

Interpretive studies that have explored the experiences of parents with intellectual disability have mostly focused on parents from the majority culture. Therefore the voices of parents from ethnocultural communities have been excluded and the influence of culture on parenting experiences and practices has been largely ignored (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008).

O'Hara and Martin's (2003) research is one of the only studies that have explored culture in the lives of parents with intellectual disability. This study reviewed the case notes of 54 parents with intellectual disability from two different cultural communities, English and Bangladeshi. One notable finding is that fathers with intellectual disability from both cultural groups did not receive parenting services unless their partner also had intellectual disability. Another notable finding was that 85% of children of mothers with intellectual disability from Bangladeshi communities remained at home compared to 29% in the English families. The authors hypothesized that there were stark differences because of the assumption that the extended social network within Bangladeshi families would be involved and compensate for parenting difficulties (e.g., presence of the maternal grandmother). The conclusion of this study is that gender and culture play a role in the way that services are offered and deserves more dedicated attention.

2.6 Summary

Research in the field of parents and parenting with intellectual disability dates back almost one century and supports several strong conclusions. Firstly, IQ is a poor predictor of parental competence; other factors such as mental health, poverty and social support appear to be more consequential (Ainsworth, 1945; Brandon, 1957; Mickelson, 1947; Penrose, 1938; Reed & Reed, 1965). Second, persons with intellectual disability can effectively learn parenting skills if teaching is tailored to their individual needs, delivered in-situ and in a systematic and concrete way (Budd & Greenspan, 1984; Feldman, 1994, 2010; Feldman, Case & Sparks, 1994, 2000; Llewellyn, 1990; Llewellyn et al., 2010; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; Tymchuk & Feldman, 1991). Third, this group of parents are disadvantaged (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; Llewellyn et al., 2010). They typically have lower levels of mental and physical health than their non-disabled peers, live in relative social and economic poverty, and are subject to discriminatory treatment (Aunos, Goupil & Feldman, 2008; Booth & Booth, 1994, 1995, 1998; Booth, Booth & McConnell, 2005; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008; Keltner et al., 1999; MacLean & Aunos, 2011; McConnell, Feldman, Aunos & Prasad, 2010; McConnell et al., 2003; McGaw, Shaw & Beckley, 2007; Tymchuk, 1994). Fourth, the experiences of these mothers tells us about how their role as a mother is central to who they are, how social support is beneficial when the support provider believes in their ability to parent and provides them with support that they want. It also reveals how mothers with intellectual disability use strategies of resistance when they face oppression (Booth & Booth, 1994, 2000; Booth, 1995; Llewellyn, 1995, 1997; Llewellyn & McConnell, 2005; Mayes & Llewellyn, 2012; Mayes, Llewellyn & McConnell, 2005, 2008; Roets, Reinaart & Van Hove, 2008; Traustadóttir & Sigurjónsdóttir, 2008; Tucker & Johnson, 1989; Traustadóttir & Sigurjónsdóttir, 2010). However, there remain significant gaps in knowledge: unchartered territories. In particular, there is a significant gap in knowledge with respect to the lives and experiences of mothers with intellectual disability from ethnocultural communities. The purpose of my study was to begin to redress this gap in knowledge. The methods employed and the theory underpinning my study are described in the next chapter.

CHAPTER 3. THEORY AND METHOD

Despite significant advances in the field, little is known about the lives of mothers with intellectual disability from ethnocultural communities (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). The broad aim of this study was therefore to explore the experience of eight mothers with intellectual disability from various ethnocultural communities who are, as Plummer (1983) put it, "living within cultural cross-roads". In line with Booth and Booth's (1994) research, this study employed narrative methods to elicit, record and reconstruct the narratives of mothers with intellectual disability from ethnocultural communities in Quebec and Alberta, Canada. Intersectionality theory was used as a lens to expand understanding of how oppression and resistance played out in these women's lives. As Phoenix and Pattynama (2006) explain, "Intersectionality foregrounds a richer and more complex ontology than other approaches that attempt to reduce people to a single category at a time, it treats social positions as relational, and allows personal narratives to be connected with socio cultural contexts; in this sense it aims to make visible the multiple positioning that constitutes everyday life and the power relations that are central to it (p. 35).

3.1 Intersectionality Theory

Intersectionality theory comprises a way of conceptualising identity and oppression/s. The theory took shape in the 1970s and 1980s initially as a corrective to 'race-blind' feminist theory and activism, and more generally, to 'single axis' (e.g., focusing on gender *or* race *or* class) approaches to the study of social inequality. Black feminist scholars, such as Kimberle Crenshaw (1989) and Patricia Hill-Collins (1990, 2000) argued that oppressions of gender, race and class do not operate in isolation, but instead intersect, mutually reinforcing and shaping one another. The experience of black women in America could not therefore be understood simply in terms of being a women or being black (gender + race). Rather, these scholars asserted that to understand the complex realities and lived experience of black women we have to consider how the oppressions of gender *and* race *and* class (i.e., gender x race x class) interact, creating 'fusions' of multiple forms of vulnerability and discrimination.

By the turn of the century, researchers were applying intersectionality theory as a framework for understanding interrelationships between the oppressions of gender, race, class *and/or* other categories of difference, such as sexual orientation, (dis)ability and ethnicity. There is diversity in this literature with respect to how intersectionality is conceptualised and applied and whether intersectionality is a theory, theoretical framework or perspective (Cho, Williams Crenshaw & McCall, 2013). Some scholars have argued that it is not a theory as it does not have variables to be operationalized and empirically tested (Cho, Williams, Crenshaw & McCall, 2013; Crenshaw, 1991). Other scholars such as Collins (1990, 2000) and Davies (2008) agree that intersectionality theory does not provide written- in -stone guidelines however as Davies (2008, p.79) argues "intersectionality has precisely the ingredients which are required of a good feminist theory. It encourages complexity, stimulates creativity, and avoids premature closure, tantalizing feminist scholars to raise new questions and explore uncharted territory". Though intersectionality theory can be seen as ambigious, some common or core premises can be abstracted. These include:

- 'Axes of identity' function as 'axes of inequality'. Opportunity *and vulnerability* (e.g., to disease, exploitation, poverty) are unequally distributed along the lines of gender, race, class, and so forth. In other words, due to factors beyond their control, some people are treated differently, and have *relatively* less power (i.e., less opportunity, resources, respect) to influence or shape their own destiny, or the destinies of those in their care.

- A person's identity is irreducible to the sum of neatly divisible parts. *Gender, race, class and other social-categorical hierarchies are not analytically discrete hierarchies: Oppressions of gender, race, class and so forth are interconnected and interdependent.* The implication is that we cannot disaggregate gender, race, class, sexuality, *etc,* for the purposes of measuring the unique contributions these make to social outcomes. Jordan-Zachery (2007, p. 261) illuminates the point, "(w)hen you look at me, what do you see: a women who is black or a black women?... In my eyes, this is a moot question since by blackness cannot be separated from my womaness".

- *Within* any given (historical- social) setting, the lived experience of, say gender or disability, may vary depending on ethnicity, class, sexuality *and so on*. Veenstra (2011, p. 3) observes that "experiences of gender are racialized, sexualized, and classed; experiences of class are gendered, racialized, and sexualized, etc." Similarly, Yuval-Davis (2006, p. 565) asserts that "(t)here is no meaning to the notion of 'black', for example, which is not gendered and classed, no meaning for the notion of 'woman' which is not ethnocized and classed…" .

- Gender, race, class, and so on, are deeply interrelated, but these are not always equally visible and/or important with respect to person's self-definitions or social outcomes. One identity may have salience over other identities for a given time or in a certain context (Cole, 2009; Collins, 1990; Torren, 2009). Samuels and Ross-Sheriff (2008) observe that the relationship between identity, interlocking oppression and power can vary depending on context and agency. They contend that context can alter social interactions and can shift, sometimes temporarily, the way in which power and privilege operate. Nnaemeka (2003) uses a chameleon metaphor to illustrate the fluidity of identity. Chameleons can change their color depending on the environment, and although their color might change to camouflage their presence, it still remains a chameleon. This could be applied to mothers with intellectual disability. For example, when these mothers give birth to their first child, this act could serve as a transition to adulthood, where their intellectual disability might be temporarily muted, though they remain a woman with intellectual disability (Booth & Booth, 1994).

- The way in which gender, race, class, sexuality, disability, ethnicity and so forth are experienced, and the ways in which these categories of difference simultaneously structure and 'emerge out of' social interactions, can vary across (historical-social) settings. One implication is that categories of difference or 'axes of inequality' are not essential, naturally given, stable or (entirely) deterministic. Identity (e.g., what it means to be a disabled women) can be made and unmade, internalized and contested, claimed and rejected (Collins, 1986). In short, the oppressions of gender, race, class, disability, and so forth, can be, and are resisted.

3.1.1 Matrix of domination

Collins (1990, 2000) was one of the first Black Feminist thinkers to expand understanding of the ways in which oppression and privilege operate within what she calls the "Matrix of Domination". More specifically, the matrix of domination allows for an analysis of how "…systems of race, social class, gender, sexuality, ethnicity, national identity and age form mutually constructing features of social organization, which shape Black women's experiences and in turn, are shaped by Black women" (Collins, 2000, p. 299). Though Collins (1996, 2000) puts black women at the center of this analysis, I agree with Yuval- Davis (2006) in that this theory can be applied to other marginalized groups.

Within the matrix of domination, there are three theoretical propositions. The first is that intersectionality creates different kinds of lived experiences. In other words, persons can experience oppression and exercise agency differently even if they belong to the same marginalized groups. Second, the matrix of domination speaks to the overall organization of power (oppression and resistance) within society. Third, intersecting systems of oppression are organized within four interrelated domains of power: structural, disciplinary, hegemonic and interpersonal (see Figure 1).

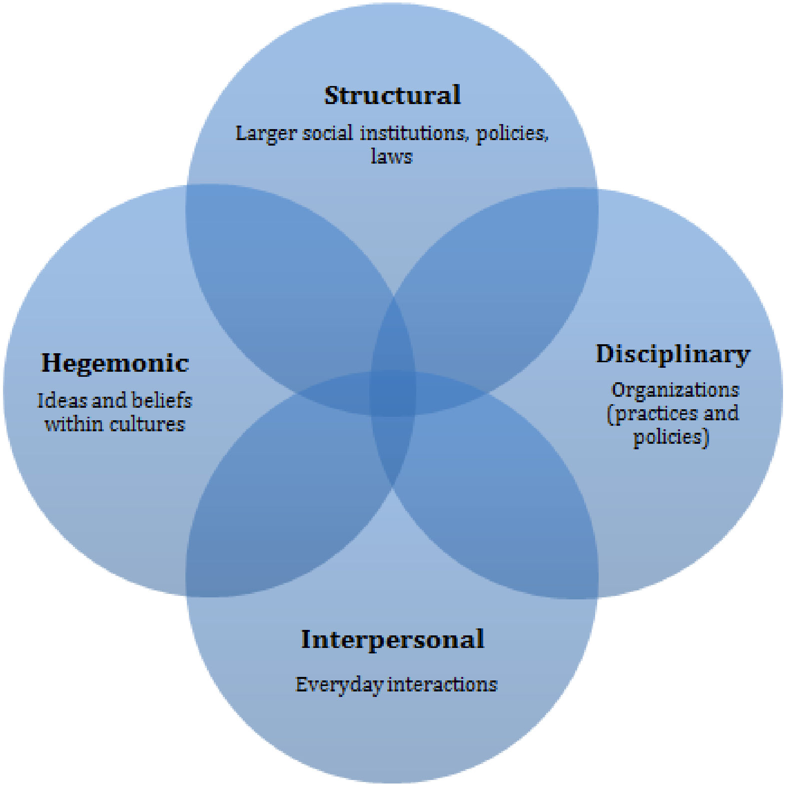

Figure 1. The Matrix of Domination (Collins, 1986, 2000)

The structural domain

The first domain of the matrix of domination is the *structural domain* where interactions take place between social location (intersecting identities) and larger institutions. This domain helps us understand how social institutions are organized and how they reproduce oppression through laws and social customs. Policies and laws advantage some members while disadvantaging others (Collins 1986, 2000; Crenshaw, 1993). From this perspective, policies and laws run according to the interests of the majority population and help maintain the status quo. Collins (2000, p.94) further notes "courts determine which narratives are legitimated and which ones remain censored and government agencies decide which official interpretations of social reality prevail". The structural domain regulates human actions through 'routinization, rationalization, and surveillance' (Collins, 2000, p. 139). That is, the structures in society solidify oppression by making it a 'normative' practice, rationalize it by implementing laws and policies that reinforce it, and then use surveillance to ensure (through fear and sanctions) that status quo is maintained.

Disciplinary and hegemonic domains

The *disciplinary* and *hegemonic* domains are where ideology and consciousness about human relations are created and sometimes sustained. Within the wider community, ideas are created about what it means to be ideal members and outcasts of society. This binary thinking places some members of society within the "normal" category and all others as "deviant" (Collins, 2000). These ideas are represented in the language that we use, the images that are reproduced within society by different media, and the values we hold. These ideologies, as Collins (2000) puts it, are often taken for granted ideologies that are deeply embedded within large social structures and social interactions. Persons that have been identified as being "less than" because of belonging to marginalized groups are sent messages about who they are and what is expected of them from different levels of society. These expectations shape interactions between and amongst social groups, and can result in unequal power relations. Collins (1996) further argues that these messages are so embedded within culture, that it can be difficult for persons that are oppressed to even recognize these social dynamics.

Persons and groups that are oppressed often internalize the stereotypes that are held by society. Pauli Murray (1987, p.106) describes how oppression is sustained and describes how systems of oppression operate as “it draws much of its strength from the acquiescence of its victims, who have accepted the dominant image of themselves and are paralyzed by a sense of helplessness”. Though Collins (1990,2000) acknowledges the vicious cycle of oppression, she like many intersectionality theorists believes that people are rarely powerless and that effective change can occur through action. This will be further explored in section 3.1.2, where acts of resistance will be discussed.

The interpersonal domain

The interpersonal domain within the matrix of domination includes the everyday experiences and actions of individuals and their families (Collins, 1990). Within the interpersonal sphere, Collins (1990) argues that tensions can emerge between the hegemonic sphere (stereotypes) and everyday experiences. This is where persons can develop critical consciousness in that, individuals, groups and communities reflect upon themselves, social interactions and their everyday lives and begin to see the contradictions between how others define them and how they define themselves. Collins (2000, p.111) further states that “Black women’s lives are a series of negotiations that aim to reconcile the contradictions separating our own internally defined images of self as African American women with our objectification as the Other”. Collins (1990) concludes that interpretive research that aims at accessing the voices and everyday experiences of persons occupying multiple inter-related social identities contributes to critical consciousness. This, Collin’s (1990) contends, is the first step in eradicating inequality. Collins (2000) also believes that shifts in thinking can change the way we act and interact, and altering behaviours can change thinking.

3.1.2 Resistance

Another important facet of intersectionality theory is agency, “where there is power there is also resistance” (Collins 1990, p. 23; Roets, Reinaart & Van Hove, 2008). In other words, a person that experiences intersecting levels of oppression is not only oppressed, but can also be the oppressor or can exercise agency within certain contexts. Agency refers to a person’s ability to engage in resistance, whether in overt or covert ways, when embedded within power relations (Yuval-Davis, 2006). Collins (2000, p.290) further notes “Such thought views the world as a dynamic place where the goal is not merely to survive, to fit, to cope; rather, it becomes a place where we feel ownership and accountability”. Collins (2000) places the responsibility of social change in the hands of both the oppressor and the persons and communities who are oppressed. Collins (2000, p.129) uses the words of Nikki Giovanni to further illustrate her point on responsibility: “We’ve got to live in the real world. If we do not like the world we are living in, change it. And if we can’t change it, we change ourselves. We can do something”.

Collins (1986) states that critical consciousness is a beginning act of resistance. Being critically conscious also allows for an examination of how identity is formed. More specifically, how external forces can shape and constrain identity. Exercising agency can take on different forms; from acknowledging and naming oppression, reconstructing definitions of self that is based on personal experiences, to speaking and or taking concrete action against oppression. This can be done by individuals, groups and communities. Collins (2000, p.132) argues that group action has received more attention in the struggle against oppression, however, personal journeys toward self-definition deserve more attention “Because our actions as individuals change the world from one in which we merely exist to one in which we have some control, they enable us to see everyday life as a process and therefore amenable to change”.

3.2 Studies that employ intersectionality theory

Within the past decade, researchers have utilised intersectionality theory to study the interrelationship between personal experience and socio-cultural context (Björnsdóttir & Traustadóttir, 2010). Some of these studies have included disability within their analysis (Björnsdóttir & Traustadóttir, 2010; Connor , 2006; Grue & Laerum, 2002; Malacrida, 2009; McDonald, Keys & Balcazar, 2007; Nind, 2008). These studies explore the insider’s perception of dominant narratives on normalcy and disability, how their version of ‘self’ often conflicts with the grand narrative of disability, and the ways in which individuals respond to discrimination and oppression (Björnsdóttir & Traustadóttir, 2010).

One such study is Malacrida’s (2009) qualitative study involving 43 women with various disabilities who were mothers to children under the age of 18 years (who had and didn't have custody of their children). The women in this study had different impairments including physical impairments (multiple sclerosis and spinal cord injuries), mental health disorders, cognitive impairments (brain injury, developmental disabilities), and/or sensory impairments (blindness and deafness). This study focused on how women with disability 'reconcile the demands of ideal mothering' with the reality of being a mother with disability. The study found that the women held themselves up to the arguably unrealistic and oppressive standards of 'ideal mothering', (i.e., to be sufficient for, and self-less in meeting their children's needs) and suffered for it. The women were conscious of their limitations. Women with intellectual disability, for example, reported having difficulty helping their children with their homework; and, women with physical disabilities reported difficulty dealing with 'run away children'. However, the women did not necessarily attribute their challenges or limitations to their disability. Rather, the women described ways in which they were 'disabled' by the physical and social environment. Furthermore, and for the most part, the women had come to see their disability as an advantage, especially when their children had a disability. They perceived that their own experiences helped them understand their children, and they saw their own challenges and triumphs as providing important life lessons for their children.

Two other studies incorporated narrative method and intersectionality theory to investigate the experiences of young people with learning difficulties (Björnsdóttir & Traustadóttir, 2010; Connor, 2006). Björnsdóttir and Traustadóttir (2010) undertook a life history study with 23 young adults with learning difficulties in Iceland, exploring the intersections of learning difficulties, class, gender and religion. In the United States, Connor (2006) applied the 'matrix of domination' to illuminate the narrative of Michael, a young black man with learning difficulties. Both studies revealed the social construction of disability in different contexts (the school system, religious institutions and society in general) that shape, regulate and maintain social interactions and positions. Both studies speak to oppression, discrimination and powerlessness as a result of intersecting social locations and the dynamic relationship with larger social structures. These studies also highlight the ways in which the participants were able to exercise agency by recognising oppression and using strategies of resistance. Within Connor's (2006) study, for example, Michael critically examines, questions and pushes against the school system and the way in which it disadvantages black males. Michael also mobilizes support in order to fulfill his goal of graduating despite others' negative expectations.

3.3 Narrative inquiry

It is quite common for intersectionality theory to be applied in the context of narrative research (McCall 2005, Choo & Feree, 2009; Cole, 2009). Narrative research has a long history within the social sciences and has recently gained resurgence in a number of academic fields (Moen, 2006; Goodley, 1996). There are many different forms of narrative research and as a result there are various definitions and practices (Connelly & Clandinin, 1990, 2006; Riessman, 2008; Somers, 1994). Some researchers claim that the narrative approach comprises a conceptual framework, a research method, and a way of representing data (Moen, 2006). Connelly and Clandinin (2006) suggest that the narrative approach is both the phenomenon and the method. They make this point by classifying the phenomenon as the "story" and the inquiry as the "narrative". In their words, "Thus, we say that people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and tell stories of them and write narratives of experience" (Connelly & Clandinin, 2006, p. 2). Though there are a number of different approaches to narrative research, there are a number of common or core tenets:

- Narratives are stories that people construct in order to make sense of their lives
- Narratives are shaped and constrained by social and cultural context
- Narratives arise out of particular interactions and relationships
- Narrative research seeks 'what is true in the realm of subjective experience'.

Narratives create meaning

Narratives help make meaning of people's lives (Bruner, 2004; Connelly &, 1990; Plummer, 1983; Riessman, 2008). The telling of stories creates further meaning as chaotic and random events within a person's life are seen within a more coherent and purposeful life story (Bruner, 2004; Mayan, 2009). Put differently, narratives help order and shape past experiences, understand own and others actions, organizes events and links 'the parts to the whole'. Further, connections are made between actions and reactions within the lives of individuals and their interaction with different actors and social networks in their lives. The stories that people tell, tell us about who they are and who they want to become (Bruner, 2004; Connelly & Clandinin, 1990).

Narratives and context

Narratives are enabled and constrained by a range of social and systemic resources and institutions. One person's story, once analyzed in sufficient depth, represents collective stories and experiences (Booth & Booth, 1994; Bruner, 2004; Chase, 2005; Riessman, 2008). Self and reality construction within narratives are bound by the narrator's community, social and cultural memberships and are influenced by history (Chase, 2005). Thus, narratives help give voice to the emotions, thoughts and experiences of marginalized groups. Narratives also shed further light on the ways in which oppression and resistance play out in society. By telling their story, in their own way, and in their own space, narrators are put in the position of having something important to say.

Narratives are co-constructed

Narratives are "socially situated interactive performances" (Chase, 2005, p.657). Therefore, narratives can change depending on setting, actors, motivation and dynamic between interviewer and narrator. Thus, a narrative is a conjoint creative process that arises from an in-depth conversation and interpretation between a narrator and listener. As researchers engage with the narratives and seek further meaning of the narratives as they present and publish their results, they themselves become narrators. These narratives, much like the narratives of participants, are enabled and constrained by the researcher's own social and cultural circumstances and position (Chase, 2005).

The truth about narrative inquiry

The purpose of narrative inquiry is to understand personal experiences through the stories that people tell (Clandinin & Connelly, 1996; 2000). A story, narrative or an aspect of a life is not sought after in order to get at some "truth", but rather narratives represent an interpretation or a re-presentation of experiences (Bruner 2004; Clandinin & Connelly, 1996; Riessman, 1993). Bruner (2004) speaks to this point as he makes distinctions between life as lived, life as told and life as experienced. Bruner (2004) suggests that life as lived is what actually happened, life as experienced are the emotions, thoughts and interpretations of the narrator, and the life as told is the narrative itself. Narrative researchers are not primarily interested in what actually happened, they are rather interested in hearing what narrators think happened and why they think it happened. Riessman (1993, p. 22) further notes, "when talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused and get things wrong. Yet they are revealing truths. These truths don't reveal the past 'as it actually was', aspiring to a standard of objectivity. They give us instead the truths of our experiences". Therefore the purpose of narrative research is to examine meaning within the stories people tell as it provides a sense of who they are and how they act in their social world.

3.4 Narrative research and parents with intellectual disability

Many persons with intellectual disability, though not all, have difficulty communicating fluently in words. Furthermore, persons with intellectual disability may have difficulty recalling events in chronological sequence (Atkinson, 2005; Booth & Booth, 1996; Stalker, 1998). These difficulties may explain, in part, why so few narrative studies involving persons with intellectual disability can be found in the literature (Aunos & Feldman, 2008; Booth & Booth, 1998). Booth and Booth (1994, 1996, 1998) however argue, and demonstrate that, with adequate preparation and accommodations, narrative methods can effectively give voice to persons with intellectual disability. Adequate preparation includes building a relationship to increase comfort and trust, and learning the participant's communication style. The interview process must then be flexible and responsive to each individual's 'way of telling'. Accommodation strategies may include:

- Using visual prompts (Garbutt, Tattersall, Dunn & Boycott-Garnett, 2009). For example, Booth (1995) suggested that researchers could use a visual timeline to help persons with intellectual disability recount events in the order in which they occurred. Booth and Booth (1994) also suggest using family photographs to explore family life.

- Using simple and concrete questions, which may be asked in a variety of different ways (Guillemette & Boisvert, 2003), by incorporating information that is known about the participant and their current situation. For example, instead of saying, what triggered your child's tantrum? One could say, what happened before James threw his toys?

- Utilizing questions or prompts that solicit an "elaboration" rather than an explanation (Guillemette & Boisvert, 2003).

- Paraphrasing what has been said can further encourage sharing of experiences (Guillemette & Boisvert, 2003; Booth & Booth, 1994).

- Involving a support person (such as a spouse, friend or case worker) chosen by the participant. Booth (1995) sometimes employed this technique, but with caution as the other participant could take over the interview further muting the informant.

- Taking a more active role, particularly in the writing up of the participant's narratives. For example, Booth (1995) suggests cutting and pasting different parts of the person's interview transcript to form a coherent narrative. The researcher also suggests editing parts of the participant's passages in order to clarify or improve readability of the narrative.

3.5 My study

The broad aim of this study was to give voice to, and illuminate the life experiences of eight mothers with intellectual disability from ethnocultural communities in Canada. One objective was to explore the role that culture (i.e., 'stories that these women are expected to live by') has played in shaping their life experiences and self-understanding. Another objective was to explore 'agency' in the women's lives. That is, to understand how these women have resisted oppression (e.g., challenged assumptions about who they are and how they should be), and given shape to their own story.

3.5.1 Sampling

A purposive sample of eight mothers with intellectual disability from various ethnocultural communities in Quebec and Alberta, Canada were recruited in two phases. In the first phase (the pilot phase), three mothers were recruited and interviewed, and a preliminary analysis was undertaken. In Wave 2, an additional five mothers were recruited. The participants were English speaking first and second-generation Canadian mothers from ethnocultural communities, who were in receipt of services for persons labeled with intellectual disability in either Montreal, Quebec, or Calgary, Alberta. A mother was considered to be a member of an ethnocultural community if she self-identified as belonging to a community that has an ethnic or cultural heritage that was not British or French, and had some involvement in the community through cultural practices and or customs (Canadian Ethnocultural Council, 2004).

The eight women in this study came from different ethnocultural communities. Four of the mothers were born in their country of origin: Portugal, India, Vietnam and Trinidad. These four mothers emigrated from their country of origin to Canada after the age of 12 years old. The other four mothers were born in Canada but expressed having a strong sense of belonging to their ethnocultural community. Two of these are Aboriginal, one mother is Polish, and the other identifies as being Trini-Indian. The women were between 21-55 years of age. They had on average two children between the ages of 3 – 21 years old with a mean age of 13 years of age. Five of the women had at least one child living with them, four children (from three families) lived in foster homes and two children were adopted. All families except for one had child welfare involvement at some point in their lives. Three mothers were married, two divorced, two single and one mother was in a relationship.

The following is a brief description of the mothers and their families within this study.

Harah

Harah is a 35 year old mother that had an arranged marriage to Yoresh, thirteen years ago in India. She moved to Quebec when she was 18 years old. The couple has two children together, Selia who is eleven, and Hazar, who is eight years of age. Hazar has some learning difficulties. Harah’s five siblings and mother live in Quebec but she usually visits with them on religious holidays.

Maria

Maria is a single mother who is from Portugal. She has two adult children, Mary, age 20, and Manuel, age 19. Mary has an intellectual disability. Maria had immigrated to Canada as a teenager but has a strong sense of belonging to her cultural community. Both children have been in out-of-home care for the last ten years. Mary was placed in a group home for persons with intellectual disability, and Manuel was placed in foster care.

Halina

Halina is a single mother with two children, Tracey, age 19, and Michael, age 11. Both children have intellectual disability. Halina was born in Montreal but strongly identifies herself as Polish and Catholic. Halina has three brothers, one of whom lives in Quebec, and two who live in other parts of Canada.

Pria

Pria has been married to her husband, Joresh, for six years. They have a five year old son, Devang. Her marriage to Joresh was an arranged marriage. Pria is a Hindu from Trinidad and her husband is from India. He is Sikh. Her family lives in Montreal while her husband's family lives in India.

Dung

Dung is a wife and mother of three boys, Mark (21), Laurence (20) and Michael (15). She had an arranged marriage to Joe, her husband of 25 years. Dung is Chinese but was born in Vietnam. Her husband is Vietnamese. Most of Dung's family lives close to her in Calgary, Alberta.

Mary

Mary identifies as Métis; Cree, English and French. She has three children, including Elizabeth who is ten, Lisa who is eight, and Matthew who is six years of age. Mary has custody of Mathew, but her daughters were adopted out when they were two years and six months old. Their adoptions are closed. Mary lives with her boyfriend, Charles, and a supportive roommate. She rarely sees members of her own family who live in different parts of Canada.

Sheira

Sheira was raised by a white foster family, but has always identified herself as Native (Cree). She has a 13 year old daughter, Victoria, who lives with a friend of the family. Sheira has bi-weekly visits with Victoria. Sheira is currently re-connecting with her foster family after a few years of having no contact.

Cheyenne

Cheyenne is a single mother who describes herself as Trini-Indian. She has one child, a three year old son named Tyrone. Tyrone was taken from Cheyenne and placed in foster care when he was just a few months of age. Cheyenne has week supervised visits with Tyrone. Cheyenne lives close to her family and has some contact with them.

* All the names are pseudonyms.

3.5.2 How I recruited the participants

Ethics approval was obtained from the University of Alberta Health Research Ethics Board (Pro 00006699). A four-step recruitment process, which has been successfully used in previous studies (Booth & Booth 1994, 1998), was employed to ensure participant consent was fully informed.

Step 1: Potential participants were identified by Readaptation Center caseworkers in Montreal, Quebec, and by staff of a parenting service in Calgary, Alberta.

Step 2: Potential participants were introduced to the project by a caseworker who was accustomed to their particular communication style. The caseworker read the information sheet (Appendix 1) through with the mother. Mothers who were willing to consider taking part in the project then had the option of contacting me directly by phone, or, have her contact details forwarded to me.

Step 3: When phone contact was made, I confirmed that the mother had received a copy of the information sheet, and again explained what participation entailed. I emphasized that participation is voluntary; that the mother could withdraw at any time without question, and without consequence; and, that the interview material will be treated as strictly confidential. If the mother remained interested in participating in the project, I arranged to meet with her at a time and place that was convenient for the mother.

Step 4: When I met with each mother and her support person, I read the information sheet through with the mother again, and invited the mother and her support person to ask any questions that they may have. Further, I checked for understanding in two ways. Firstly the mother was asked to explain, in her own words, what participation in the project would involve. Next, using the informed consent questionnaire attached (Appendix 2), I checked that the mother fully understood what her rights were before her written informed consent was obtained.

3.5.3 How I collected the data

A total of 33 interviews were conducted over a twenty-four month period. From three to seven in-depth interviews were conducted with each mother. Interviews with each mother ceased once a coherent narrative with rich, thick description was written-up, and the mother had confirmed that the write-up/re-story authentically re-presents *her* story. This is consistent with the narrative approach (Booth & Booth 1994, 1998; Connor, 2006).

Each interview was conducted at a time and place that was comfortable and convenient for the mothers. All of the participants chose to have the interviews take place in their homes. The interviews were digitally recorded with the mother's consent and transcribed in full. The recording and transcripts are stored in a locked filing cabinet in the research department of the West Montreal Readaptation Center.

Each interview was unstructured and responsive (Mill, Mayes & McConnell, 2009). The focus of the first interview was to develop rapport and familiarity with the mother's communication style. To open the 'conversation', each mother was invited to share her family photographs. Further, in advance of all additional interviews, I developed an 'aide-memoire' (Booth & Booth, 1994a, 1998), consisting of topics to be explored in the interview, including, for example, the mother's own upbringing, (events surrounding) the birth of her child/ren, challenges and rewards of motherhood, and interactions with workers, systems and family members. This aide memoire served as a 'prompt sheet' rather than a structured plan: participants were invited/encouraged to tell their own story in their own way and at their own pace. Before each interview, the transcript of the previous interview was reviewed to identify topics/themes/issues that needed clarification or further development (Booth & Booth, 1994a; Plummer, 1983). In this way, the aide memoire was adapted to serve the needs of the emerging narratives.

In line with the narrative approach used by Booth and Booth (1994, 1998), I began the interview process with a grand tour question (Spradley, 1980) "Tell me what it is like to be a mother". Depending on the communication style of the participant, I also incorporated other types of questions: *follow-up questions* (i.e. Could you tell me more about what happened once you went home with your daughter?), *probing questions* (i.e. What do you mean about this not being a part of your culture?), *specifying questions* (What was your husband's reaction when you told him that you wanted to leave him?), and silence (Kvale, 1996). These types of questions have been shown to be effective with persons with intellectual disability (Booth & Booth 1994, Guillemette & Boisvert, 2003). Other strategies were also employed to elicit the narratives of the participants. Looking through photographs also allowed the mothers to elaborate on their relationships with family members and provided further insight into their culture. For one of the mothers in particular, visual prompts (e.g., a drawing of a road intersection, which was used to explore cross-roads within her life) proved to be helpful in increasing narration of her story.

As the interviews took place within the mothers' homes, I also had the opportunity to observe some of the interactions between the mothers and their children and partners. I was also invited to join supper, accompany them to the park and grocery store, and to pick their children up with them from school. This occurred with four of the mothers. My observations and reflections of these interactions were included in my researcher reflective logs, and I also included some of my observations in the narratives.

3.5.4 How I analyzed the data

Analyzing narratives is labor and time intensive (Gilbert, 2002, p.233). Plummer (1983, p.99) describes the process as "brooding and reflecting upon mounds of data for long periods of time until it makes sense…" In line with Booth and Booth's (1994) research, I used 'systematic thematic analysis' of the data (Riessman, 1993), where emphasis is on the content of a text, "what" is said more than "how" it is said. The data analysis within this study occurred within two phases. The first phase involved constructing the narratives from the raw data. Following the transcription of the audiotaped interviews, I immersed myself in the data by actively and repeatedly reading the transcripts. Within each transcript, I paid attention to the characters, events, plots/tension and accompanying emotions. The plot of the narrative has been seen as one of the most important facets as “plot determines what gets included in any particular narrative” (Riessman, 1993, p. 94). Polkinghorne (1988, p.12) further states that this “provides the primary source of information to examine the way individuals attribute meaning to their experiences”. In order to uncover the plot, I asked myself “what was the central conflict” and “what were some of the turning points in the woman’s life”? (Gilbert, 2002). Once I answered those two main questions, I began cutting and pasting parts of each woman’s transcripts that reflected those two questions. After I did that, I cut and pasted the other parts of the transcript. The different interviews were spliced together to form a coherent narrative (Booth, 1995). I then edited the narratives trying to keep as much of the woman’s words as possible but at the same time ensuring for readability.

Once the narrative of each woman was written up, I presented each participant with the constructed narrative to verify if I had captured *their* story as they told it and wanted it to be told. This is consistent with the techniques used by pioneers in narrative inquiry, including Clandinin and Connelly (2000).

After constructing the narratives, I re-immersed myself within the narratives. The aim of the second phase of the data analysis was to seek *the mothers’ voice*, referring to the narrative themes that ran across these women’s stories (Booth & Booth, 2006, p.95). In line with Booth and Booth’s (1994) research, I began this phase by reviewing each narrative and generating initial codes. A code is a concept that describes what is being said within sections of the data (Mayan, 2009). I coded for as many potential themes and patterns as possible within the narrative. I then reviewed the different codes, grouped similar codes together and put them into categories or themes wherever possible keeping the mothers’ own words (Booth & Booth, 1994, McDonald, Keys & Balcazar, 2007).

Though each of the mothers’ narratives were unique to their experience, there were common themes that ran across their stories, especially, as they experienced the world as mothers with intellectual disability from ethnocultural communities.

Exploring the themes across the narratives (as opposed to solely presenting individual narratives) was also used in Booth and Booth (1994, 2000) and McDonald, Keys and Balcazar (2007) studies. These studies employed these techniques in order to understand the influence culture has on the experiences of persons who occupy marginalized positions within society. This allows us to see the "personal as social" (Clandinin & Connelly, 2000).

In this study, the data is represented in narratives (ontological narratives or individual stories) and is further analyzed by making links across the narratives (meta-narratives) through an intersectionality theory lens that can be found in the results section in chapter five. This also allows for a full analysis of intersecting social identities more specifically, how oppression and resistance played out in these women's lives at different levels within the matrix of domination.

3.5.5 Rigor within my study

Mayan (2009, p. 100) states "Rigor is demonstrating how and why (through methodology) the findings of a particular study are worth paying attention to". Within this study, I employed the following strategies to establish rigor: prolonged engagement, cross narrative comparison, thick description, member checking, researcher reflexivity, and theoretical sampling (Mayan, 2009; Plummer, 1983; Booth & Booth, 1994; Goodley, 1996).

Prolonged Engagement

The traditional understanding of prolonged engagement is time spent in the field allowing the researcher to become embedded within the participant's socio-cultural context (Mayan, 2009). Booth and Booth (1994) argue that prolonged engagement is essential in building trust in order to further mutual dialogues. I employed prolonged engagement by conducting multiple interviews with each of the mothers in their home environments over a period of two years, and participating in everyday activities with them, such as picking their child up from school. Spending time like this with each participant, and observing them interact with their children and significant others, was key to developing a nuanced and contextual understanding of their life experience.

Cross Narrative Comparison

Booth and Booth (1994) suggest that one of the features inherent within narrative research, that is seeking common themes across participant's stories, functions as a validity check in the research process. "Making comparisons between families was perhaps the best technique for validating the experiential data: as one account confirms another, stories accrete and regularities emerge so it becomes less likely that individual narratives are the product of one person's fancy and more likely that they show structural features in the lives of the subjects"(p.39). Within my study, there were several narrative threads that emerged, one of them being the tension between 'keeping up appearances within their culture' and exercising agency within their lives. Another was how they defined 'being a good mother' as being influenced by the intersection of the broader social context and cultural messages from their family and community.

Thick Description

In establishing rigor in narrative accounts, many researchers have also emphasised the importance of thick description. That is, providing extensive details about the social settings and how power relations are enacted within them (Geertz, 1973; Atkinson, 1997). Maynes et al., (2008, p. 148) assert that "Developing effective strategies for making persuasive arguments based on life stories means not taking them simply at face value, but rather providing the necessary context for understanding and interpreting their possible meanings and significance and for appreciating their storied quality". Within narrative inquiry, ensuring that the subjects' voices remain dominant throughout the narrative also "makes it almost impossible to impose a view that goes against the grain of the story" (Booth & Booth, 1995, p. 140). When I constructed the narratives, I included as many quotations as possible to try and capture the mother's voice.

Within my study, I also kept a researcher's journal (Mayan, 2009) that included my interpretations, observations, hunches and insights in relation to my interviews with the mothers. I used my journal and the raw data of the interview transcripts to construct each mother's narrative, thus providing rich descriptions in order to further contextualize their experiences within their socio-cultural environment. As I employed prolonged engagement, it allowed me the time to spend with each mother and her family within the interview process and through informal dialogue (Plummer, 1983).

Within the mothers' narratives, I also interjected (when necessary) some additional context to further understand their story. For example, Harrah described the difficulty she had in helping her children with homework as it was in French, her second language. At this point in the narrative, I explain that, in Quebec, Bill 101 stipulates that all immigrant children must be taught in French as this is the province's dominant language.

Researcher Reflexivity

As narrative inquiry is based on the dialogue between the participant and researcher, and the interpretation of this dialogue, it is essential that researchers are able to reflect upon the process in two different ways. These are through the interpretation of the informant's stories and in the writing up of the narrative (Goodley, 1996). "Thus, researchers need to also confront their own perceptions of informants, if unfair, they may hinder the research process. Being sensitive to both our informants and our own feelings, perceptions and speech will make us more able to hear their stories" (Goodley, 1996, p. 339).

I reflected upon my role as a researcher and noted my perceptions, questions, and future orientation throughout the research process. The following is an excerpt from my researcher's journal. It reveals some initial reactions and musings after my first interview with Maria.

I began the interview by telling Maria that I was interested in her story, to have a better understanding of what it is like to be in her shoes. She began by telling me about her birth story. I wondered as she was telling me this story: Why did she start there? What significance does this story have? What are the underpinning meanings? What does she reveal and what is left to reveal? How does this story help me understand her as a mother? This story was filled with both high and low points, where she struggled to survive as a newborn. I think this story represents Maria's counter narrative, a re-birth, as she portrays herself as strong, important to her family and the community.

As I am asking myself these questions, I am sure in part I will be able to find some insights in the data. In her words, in her narrative. There might be some questions that I will have to ask her to expand on or clarify as I go back to her words.

(LP, Researcher's Journal, August 4th 2009)

Another way, in which I verified some of my interpretations of the mothers' stories, was by sharing them with my doctoral supervisor, fellow doctorate students and colleagues during team meetings and group discussions within the research laboratory of The Family and Disability Studies Initiative at the University of Alberta. This provided me with additional insights and allowed me to 'step back from my data' as suggested by Bruner (2004).

Chase (2005, p. 23) also encourages narrative researchers to ask what the narrative actually represents, and suggests asking the following questions within the research process: "How did the author come to write this narrative? What conditions led to this text being said? Whose views are represented?" I took note of these questions and reflected upon them as I wrote up my narratives. I also reflected upon my social location and how this may have impacted the participants and the research process. These reflections will be included in my final reflections section.

Another important facet within the narrative approach is reflecting on the researcher's story as this can impact the hearing, interpreting and co-construction of narratives (Goodley, 1996). In my reflective logs, I explored the ways in which my social position (i.e. woman, social worker, Portuguese, impairment/disability), experiences and values can impact the research process.

Member Checking

Another strategy that I used to ensure rigor was member checking. Once I had written up each of the mother's narratives, I presented the informants with the written story and asked them to confirm that *their* story was fairly represented. I also asked each of them if they wanted to provide additional information or clarify what had been written or interpreted. Most of the mothers did not want to change their narrative (It's important to explore why this was; was it because they were satisfied with the chronicled narrative, or did they see me as an authority figure and did not want to challenge me?). As we read the narratives over together, five of the mothers expressed positive feelings in regards to sharing their story. Sheri (IT 3, pg. 9), for example, said "*Nobody has been interested in what I has to say, no one has been interested in my story".*

Theoretical Sampling

Theoretical sampling is most closely associated with the grounded theory tradition (Glaser & Strauss, 1967), but it has also been used in narrative approach (Booth & Booth, 1994). It has been defined as "as the process of data collection whereby the researcher simultaneously collects, codes, and analyses the data to decide what to collect next" (Coyne, 1997, p. 625). I employed theoretical sampling throughout. After each interview, I transcribed and commenced analysing the data. Inconsistencies or 'gaps' in the participant's account were identified, as well as emerging themes that required further exploration and development. I then revised my aide-memoire to ensure that such inconsistencies or gaps were addressed in later interviews. I also employed theoretical sampling as I moved from the pilot phase to the second phase of the study: the analysis of the pilot phase data informed the development of the aide-memoire used in the second phase. Specifically, after phase one it was clear that I needed to explore, in greater depth, topics such as the cultural interpretation of intellectual disability, the meaning of child welfare involvement, and everyday experiences of motherhood.

3.6 Summary

The broad aim of this study was to illuminate the lives of eight mothers with intellectual disability from ethnocultural communities in Canada. This research was inspired by the methods used in Booth and Booth's (1994) landmark study, with the objective of further understanding the dynamic interaction between cultural context and lived experience. The rich and descriptive narratives of the eight women in this study will be the focus of the next chapter.

CHAPTER 4. THE NARRATIVES

4.1 Harrah's Story

"Stay still Selia". Selia squirms and moves her head to the left". It's going to come out all crocked if you move!" "It hurts mama". Harrah looks at the back of her daughter's head with a stern look. If you don't move it will be quicker. Harrah pulls her daughter's long black hair in order to make a tighter braid. "My mother used to do this with me and my sisters every day. When we were back in India. Selia complains a lot when I do it. But we had no choice growing up. All the girls had their hair this way." (LP, reflective log, August 5th 2009).

I learned at an early age what made you a good Indian girl and what made you a bad Indian girl. This is a big part of my story. My name is Harrah and I was born in India. I am a mother and a wife. I have two children; Hazar 8 years old and Selia 11 years old. I have been married to my husband Yoresh for 12 years. We had an arranged marriage. Both my husband and me were born in India (Gujarat) and my kids they were born in Canada. We are Hindus.

And this is my story.

Growing up in India

I was born in a small village in India, called Gujarat. I have eight brothers and sisters and I am the middle child. I went to a regular school with my brothers and sisters and we walked to school every single day.

I have very good memories of growing up in India. It was always warm. I remember the hot sun that would shine on my face. I remember helping my mother cook in the kitchen and the smell of curry throughout the house. We made things like chapattis and chicken masala. I loved cooking with my mother. My house was never empty. We always had family or neighbors visiting. We also liked to go the festivals or religious events in the village. We were a close family.

When I think of India, I think of home. India is my country. India is always where I wish to be. When my life was simpler "when I didn't have all of these problems" (IT 1, pg. 7).

When Harrah spoke about India her eyes lit up as she spoke about times that were near to her heart.

I remember feeling Iike I was a part of my family. That I wasn't stupid or lazy. Whatever my family was doing, I was doing. In school it was the same thing. I was there with everybody else. I don't remember feeling different.

Harrah described a good upbringing; where she felt very much a part of her family and community. Her family had talked to her about marriage and children just as they did with her sisters. It wasn't until later on in her life that she felt different, that there was something wrong with her; that she was different from everybody else in her family.

Coming to Canada

Leaving India to come to Canada was identified by Harrah as an important moment in her life. She was 15 years old and was excited at the thought of a new life yet scared because of what she was leaving behind.

My older sister was the first to come to Canada. After a few years she would sponsor my mother, father and me. My older brother would also come to Canada one year after we moved. The rest of my family members would stay in India.

"My mother told me that I would be going to Canada with them. I had no idea where Canada was. I had no idea that it was so far. That it was so different. But they said that we would go and have a better life. My sister and her husband bought a nice big home in Canada. And maybe we could too" (IT 1, pg. 2).

Adapting to her new life in Canada was difficult for Harrah. Her family had described to her all of the good things about her new country but had left out many of the things that she would have to adjust to…

Coming to Canada was hard. I left my country and some of my brothers and sisters. I did not know what Canada was like. But my sister said that it was cold. She was right, it was really cold! I had to wear many sweaters with a really warm jacket.

I remember when I first came how the streets were so busy, the cars were so fast. It was so loud too.

I remember when I saw the apartment; it looked very different than my house in India. My house in India was all open. It was like it did not have any doors or windows. Anybody could come in. But it was safe. The apartment in Canada was small and everything seemed so close together.

As soon as I got to Canada, they wanted me to go to school. They did some tests to find out which school I would go to. After the testing, they told me and my family that I had a handicap; that I had to go to a special school for people with handicaps. It was the first time that we were told that I had a handicap or the first time that we talked about it. I still do not know what that means. That I have a handicap.

After the school told us that I had a handicap my brothers and sisters would call me lazy. Or they would scream at me to do things faster. I think they blame me for what has gone wrong in my life. I don't think they understood that I was not doing things on purpose. That this is the way I was. This is the way I am. And some of it I just can't help.

Shortly after coming to Canada, when I was 16 years old, one of the worst things happened in my life. It is something that I cannot forget. That I will not forget. I don't want to ever forget him.

One day after school we would get a terrible phone call. My mother answered the phone. She was speaking and screaming in Gujarati. I knew that something really bad had happened. I saw it in her face. I heard it in her voice. She started to scream "oh no not Nari. Not Nari" (IT 1, pg. 9).

My mother told me that my youngest brother Nari died in a bicycle accident in India. That a car had run him over. And that he died right away. And she cried and screamed.

He was my favorite brother, the one that was the nicest to me. The one that I felt loved me the most. He was too young to die. And I never got to say goodbye.

I also could not go to his funeral. My parents did not want me to go. They said that they did not have the money. I would not be allowed to go to the burning of the body ceremony. "But men only they can see {the body}, as women they say they are too weak. They cry too much" (IT 1, pg. 2). I don't think they wanted me to go. Maybe they thought I was too weak.

I miss my brother even to this day.

Being born two times

Harrah always knew that she wanted to be a mother. She also knew that in order to be a mother she needed to become a wife. It was something that was talked about and expected in her family. She had gone to many weddings of her sisters, her cousins and people in her community. They were all arranged marriages. And Harrah wanted that too.

Some years after moving to Canada, when I was about 24 or 25 years old, my parents and my uncle in India would start making plans for my marriage. They said that I was getting too old. That if I didn't get married soon that not a lot of men would want to marry me. I knew that if I got married, that this would mean that I would have children.

"In my culture, in India, women they have children, yeah, that's what they do. If you don't have babies then you always live with your parents. Very important thing that I knew that I wanted children" (IT 1, pg.3).

I didn't know who I was going to marry. But I was ok with that. That's the way that they do it in my culture. In my family. My uncle had found my husband- to- be in India. He was from the same village and was the same age as me. They told me that he was a good match. My parents encouraged me to marry this man and that this would make them happy.

In my country it is the parents that find the husband for their daughters. It is important to make the family proud. You cannot have a boyfriend, you must get married, that is the way it is. The only way.

Harrah agreed to go forward with the marriage because she wanted to have a family. Going to India to meet her future husband was another stepping-stone towards adulthood. It was the first time that she was separated from her parents. It was the first time that she went anywhere alone.

My parents would send me to India to meet my husband before we got married. They would not be able to come with me, but they wanted to. My father got sick and he needed to have an operation. My mother had to stay with him to help take care of him. It was hard for me not to have them with me as they were always there for the important things in my life. I did not want to meet this stranger without them. But I could not say no, especially as my father was sick.

Harrah felt increased pressure to meet her future husband as her father was sick. If anything would happen to her father, at least he would know that Harrah was following traditions and the family's wishes.

Harrah spent her first few days in India visiting family.

After a few days in India, I would meet my husband to be at my uncle's house. When I first saw him I did not like what I saw. He was too short. He also made me shy. I didn't know what to say. When I told this to my parents they told me to keep going, that I would like him. They told me some stories of people that they knew who had felt the same thing. But now they are happy together.

So I kept meeting him at my uncle's house and then I saw that he was nice and had a nice smile.

I remember my mother telling me that "a woman she is born two times. Once when she is born and once the day she marries her husband. Her husband has given her the life" (IT 3, pg.4). My mother told me it's like you have a new life. With your husband. And that you must respect him. Love him. And take care of him. The same like Canadian woman but more. Indian women should stay home. To take care of the house and family. And only if the family does not have enough money should the woman work (IT 3, pg.5).

The wedding day took place a few weeks after I met my husband.

Harrah went into great detail about the cultural traditions within marriage. She had asked me if I had ever been to an Indian wedding, when I responded that I had not, her face brightened "You will know about it now".

The wedding lasts a few days in our tradition where we have different religious ceremonies. That is also when the women gets a Bindi, a sign that she is married. I also had henna put on my hands and I would wear different saris. The sari that I wore for my wedding was bright pink, with gold embroidery. My mother had kept it for me; for the day that I would get married.

Harrah showed me some of her wedding pictures with great pride. She looked beautiful. Her bright pink Sari was complimented by her bright makeup. As I looked at the pictures, I noticed that neither she nor her husband were smiling. She commented that they were scared.

I felt many different emotions that day. I was more nervous than happy. Even though many of my family members were there, my parents and my brother were not there. I understood why they were not there and also worried for my father. There were also a lot of people that I didn't know. Many family members from my husband's side that I had never met before. I think there were about 1000 people there. At my wedding.

It was a long few days. After the final wedding ceremony, we would go to my family and my husband's family's house. We would go for supper and we would receive gifts for our marriage. I would stay with my husband's family. I felt shy, as I did not know them like I did my family.

My husband and I would share the bed for the first time.

Harrah described the moments leading up to spending the night alone with her husband. She knew that they would be intimate, but couldn't imagine what that would mean. When I asked her if this was something that was discussed with her mother or sister, she just laughed.

After the tenth day of being in India, I would go back to Canada.

My husband asked my uncle for me to stay longer but I already had my plane ticket. I would come back to Canada to save some money for me and my husband. And for the family we would have one day. I worked in a clothing factory with my older sister. I was not supposed to work, but in Canada, women worked and I would work at least until my husband would join me in Canada. I already had some money saved and while my husband was in India, I would save $15, 000. I was proud that I had saved this money.

My husband stayed in India while I worked in Canada for one year. We would write each other letters and talked on the phone every week. It was weird for me because we got married, I stayed with him for a few days and then came back home. We were married but we didn't live like husband and wife right away.

While I waited for my husband, I still lived with my parents. My mother taught me again how to make some food like chapattis and Indian vegetables so that I can cook for my husband. That is the role of the woman. To take care of her husband. To take care of the older people. To take care of the children and take care of the home.

Once my husband came to Canada, my brother found him a job in a factory. We lived with my parents for few months until we found our own apartment in the same neighborhood. Even while I was living in the apartment with my husband my mother would help me in the home especially while I was working. She would do a lot of the cooking and cleaning.

After working a long day it was hard for me to keep up with my housework. I was not supposed to work for a longtime, my husband was supposed to take care of me. But since we were trying to save money I kept working until my daughter was born.

Saving money was important for Harrah. She wanted to buy a house. She wanted to have money to send to her husband's family in India and she wanted to be able to visit her family in India.

The stars in my life

Having children was described as the most important events in Harrah's life. She described feeling whole, when she had her children, as if before she knew that there was something missing.

After a year of marriage, my daughter, Selia was born. It was not planned but I was very happy when I found out that I was pregnant. My parents were not too happy when I told them that I was pregnant. They told me that I was too young. They wanted me to have an operation, an abortion. I think they thought I could not do it, that I did not have enough experience. But me and my husband we wanted to keep the baby. It was our baby. It was our first born.

Before both my children were born, my sister-in-law chose the names of my children. She really liked Bollywood movies and it is believed that the names you give your children will follow them for the rest of their lives. My sister-in-law gave both my children Bollywood movie star names.

Maybe they would become stars one day.

When I was pregnant with my daughter, because it was the first one, it was strange the way my body was changing. No one had warned me about that. I did talk to my sister. She said that it was normal. I felt reassured.

Giving birth was nothing that I could have prepared myself for "it was the most painful thing to have the contractors {contractions} and then to push. Very painful. Very painful" (IT 1, pg. 5).

Harrah, like many parents, described her fear in caring for her daughter after she was born. Being in the hospital was one thing and then going home was another. She questioned her ability to care for her daughter. Would she know what she wanted when she cried? Would she hold her properly? She felt some comfort in having her mother and sister with her much of the time.

I was nervous after my daughter was born but I had my sister and my mother who were with me a lot. They would help give Selia her bath, change diapers and feed her. This was how I learned the things I needed to know to be a mother. My husband would play and feed Selia but he never changed diapers. I was ok with that.

I was happy after my daughter was born. My husband seemed happy too. I felt I was a good mother to Selia. I felt like things were going ok. My husband looked happy and I think that he thought I was a good mother. I think my family thought I was a good mother. It felt good that my family was happy.

This would all change when my son was born. He was born three years after my daughter. It's hard for me to remember everything. It all seems a little fuzzy. I had a depression after Hazar was born. I think it's because of all the money problems we were having. I found out that my husband gambled all the money that I had saved just before I gave birth to Hazar. The $ 15,000 that I had saved was gone. I was so angry and hurt. I had saved this money so that maybe we could buy a house one day.

After I found out about the money, we were fighting all the time. He would stay out late and he would come home with no money. I had stopped working and did not have much money of my own. I was on welfare but then we got in trouble because my husband was working at the same time.

When my son was born, it was not a happy time. It was difficult for me to get out of bed. I could not even feed him. It took too much energy. I was very worried about the money, so worried that I think it made me sick. The gambling problems became more memorable than my son's birth.

The professionals at the hospital saw Harrah's difficulties and they contacted youth protection. Harrah did not understand why they had contacted youth protection and why they were intervening in her "family business".

A parenting capacity assessment was also completed while Harrah was in the hospital with her son. Her diagnosis of an intellectual disability was re- confirmed.

The nurses would not let me leave the hospital unless my mother promised to move in with us. To help me with the babies. They said that they would let me have the children if my mother helped me out.

Harrah felt relieved that her mother would move in with them. And at the beginning, her husband also thought that it would be a good thing. Harrah described her husband as initially worried about her. He knew that she was not the same woman that he married. But all that seemed to change when he realized that the way she was not going to change.

My mother moved in with us after I came out of the hospital. I also received services from the community center. I had help from a lady who came to help me feed and take care of my son. My husband was working long hours at the factory so he was not home very often. During the day he would sleep. He was doing the night shift. My husband seemed worried about me at the beginning. He would ask me what he could do. But then it was like he didn't care. He also started to call me lazy and stupid. He started calling me names because I wasn't taking care of Hazar on my own. He was also upset that I would sleep a lot during the day instead of doing housework. I don't think he understood what was happening to me.

I think this is when my marriage began to fall apart.

Harrah explained that her husband started to treat her differently once he realized that her ability to care for the children and the house was not just a temporary thing. Harrah's inability or difficulty maintaining these tasks independently seemed to go against her husband's perception of a good wife and mother.

We would fight all the time, I would complain about his gambling and he would complain about the housework not being done. Or that I had missed a spot. My mother tried to stop the fights and get in between us. But it didn't always work. My brothers and sisters tried to help us by giving advice. But we were not ready to listen.

After that, my family did not want to see or talk to us very much. I felt abandoned by my family. It would take about one year, before I started to feel less depressed. But the feelings of sadness stay with me today.

When Hazar was about one years old, he had to have surgery. On his head, but not his brain. I was just starting to get out of my depression, but I still was not feeling well. I just remember thinking 'please don't die, you are my only son' (IT 2, pg. 3).

He was my son, and sons are very special. Sons they never leave their mothers, even when they get married. Hazar was so special to me and I would never say this to Selia but Hazar is my favorite. Maybe because of his sickness. Maybe because he is a boy. Maybe both. The surgery went well and we would never have to worry about Hazar's physical health again.

Harrah also described the importance that boys and males have in her culture. I also saw this in her interactions with her children. During an interview on September 6th, I had noticed that both her children had left their snack on the floor in the living room. She asked her daughter to pick both of the plates off the floor. Selia groaned and asked her mother "why do I always had to do everything". Harrah responded by saying "because you are a big girl". When I asked Harrah what she meant she told me "that's the way it is in my culture" (LP, reflection Log, September 6th 2009).

Children growing up too fast

Seeing her children growing up only meant that Harrah wanted to keep them closer to her. The older they got and the more responsible they got, reminded Harrah of the inevitable; that they would leave home. And that she would be alone.

It's hard for me to see my kids growing up. They are my life. They have grown up so fast. I can't believe that they are already 11 and 8 years old. It's sad to see them growing up because I think that this means that they will soon be away from me. That they will leave me. When they are away from me, even if they go to my brother's house for a few days, I would get lonely. Before the kids, I was lonely and when the kids are close to me I don't feel so alone.

I love my kids but they do not always listen. I want them to listen to me, to listen to what I have to say because that's what children are supposed to do "listen to their parents". But they do not always listen. They listen more to my husband, I think it's because he has a big strong voice.

My husband tells me it's my fault that the kids don't listen to me. I sometimes think that the children are too young; they are too young to follow strict rules and take care of the house. The parents, or mother, should do this for them. But my husband does not agree and he also tells me that I am a bad example to Selia. That she is not learning how to be a good wife or mother from me. That she will be lazy because I am lazy.

"I don't think that's true. Sometimes I might be lazy, but I always have to do everything in the house even when I am working like my husband. He is only happy 'when I go to shopping or when I clean the house. Something like that. He likes when I do that and when I do it good" (IT 4, pg. 2).

We try to do family activities together. Sometimes we will go to our religious community or we will celebrate at my brother's house. When they invite us. We also like to go to Jarry Park or go to the beach to have BBQ's with other Indian families. Sometimes my husband will bring the kids without me. Sometimes I think that he is embarrassed of me. When we are out he always tells me not to yell at him in public. He tells me not to say too much. To stay quiet.

I asked Harrah why her husband would ask her to do that, to stay quite. She told me that "Indian woman are supposed to listen". She gave me her mischievous smile when she said that. I responded to her, "I guess you don't always listen". She nodded her head and smiled.

Harrah also expressed her difficulty in helping her children with their homework. One of the issues is that in the province of Quebec, all children of immigrant parents, whose parents did not attend school in Quebec, have to send their children to a French school, even if the family's second language is English and not French.

I try to help my kids with school but it is not always easy. They both go to school in French. I don't understand French. The teacher will sometimes write a note in the agenda, but I don't understand anything.

Selia is doing well at school, but they want her to stop missing school. I know that it is a problem and I am trying to be better with that. Now that I am working right beside the school it is easier for us. Hazar has "I don't know, but learning and maybe the writing problems, with his letters they are not that straight. But I don't think it a big problem. I had some problems too." That's what the school says that Hazar is a little bit behind. I think he is smart but some things like writing are more difficult. I had difficulties in school too, so I think he will be ok. I hope that they will be ok.

The school is aware that Harrah has an intellectual disability. They realize that the parents might have difficulty supporting their children with their homework. They suggested the children's integration in the after school homework program.

The teachers also told me that Selia is shy. Selia will sometimes come home from school and cry. She will tell me that 'the kids at the school call her a pig. That she looks like a pig. I don't know why they have to say that. It makes her cry" (IT 3, pg. 5). The workers tell me it's important for her to have clean clothes. For her to have clothes in her size. Because the kids are mean. They make fun of kids that are different. Or when you look different.

I don't know what to tell Selia when this happens. I don't like to see her cry. But I know how she feels sometimes. When people say things about you. And making fun of who you are.

When it got bad

Since my son’s birth my husband and I have been fighting a lot more. There are times when we fight less and times when we fight more. It hurts me a lot to think that the machines that my husband gambles on are more important than me and the kids. Sometimes he spends more time with the machines than he does with us. I started to scratch tickets too. When it was at its worse I could spend 200 $ on scratch tickets each week.

The money problems are the worst thing. When my husband gambles it makes me upset. And this makes me want to gamble and not clean the house. This makes him more upset. I also gamble because my dream is to win. If I win then we could move to India. And everything would be better. That I could save my family from the problems. I don’t think my family likes what was happening between me and my husband. They did not want to see us anymore. No one wants to give us any money either. I don’t know, but I feel that my family doesn’t care about me. Maybe they care about the kids, but they don’t really care about me.

Everything, all of this, is inside of me. One day, about five years ago, me and my husband were fighting. We were screaming, yelling and I went to push my husband. Hazar was screaming at us to stop. Selia was there too, she was crying on the couch. But I was so upset at my husband; he wouldn’t give me any money because he had gambled it all. I was upset. I was frustrated. And then I did something that I didn’t want to do. I pushed Hazar. And when he did not move, I hit him. I never wanted to hurt my son. My children are the last people that I would ever want to hurt. I was just very angry. I wanted my husband to listen to me. For once.

Harrah’s voice trembled as she recounted this story.

The neighbors downstairs heard the fighting and they called the police. We didn’t want to open the door. But the police just kept banging. And then they said they were going to kick the door down.

I was so afraid.

The police had come a few times before this, but this was the first time that I hit my son. Everybody was crying. I was screaming when the police came. They asked each of us what happened. I told them the truth. That I was angry at my husband and I hit my son.

I didn't want to hurt my son.

They told us that they would have to call youth protection. And they told me that I had to move out of the house for a little while. That I would not be able to see my children. After a lot of convincing, my brother accepted that I live with them for a little while. Youth protection told them that he had no choice; I had nowhere else to go.

I lived with my brother for about two weeks. I was able to see my kids only if my husband was there. My brother lived far so I could only come to see them when he could drive me. I would speak to my children on the phone. Each time I would call, Hazar, would cry. He would ask me when I was coming home. He would make me cry. Each time I called 'I was very sad'. I hated being separated from them. But I had no choice.

Me and my husband were talking about a divorce. But I was scared. If I divorced my husband, maybe I would never be able to see my children again. I remember youth protection told me that because of my handicap and medication that I would not be able to take care of my children alone.

I would never forget that.

Sometimes divorce from my husband sounds like a good idea, but then I could lose my children. It would also make my family unhappy. Youth protection agreed that if my mother moved back in with us that I would be able to move back in to my home. So my mother moved back in with us.

I was very happy to have my mother move back in with us again. She would help me cook and clean. She was always there if I wanted to talk. She would also try and protect me when I was fighting with my husband. I think we even fought less when my mother was around.

The kids too they love their 'baba'. The youth protection workers were ok too. They said if we fight less with the kids, make them good lunches and get them to school on time that they would soon close the file. I didn't like having those workers in my life, either did my husband, but they helped with some things. They wanted us, me and husband, to talk more to each other instead of fighting. Fighting they said was bad for the kids. "They {the kids} hear us fight about it. And sometimes they will cry and tell us to stop. That's not good" (IT 4, pg. 6).

We have had a few youth protection workers since then. Over the last five years, I think they have opened and closed our file a few times. The last youth protection worker was nice. She listened to what I had to say and she was like my friend. I have never had any real friends. "I don't have nobody. Only I have my family, that's it. I don't have nobody" (IT 4, pg. 4).

My mother stayed with us for about one year and a half.

One day while me and my husband were fighting, my mother tried to come between us. I wouldn't listen, so she came close to me and told me to stop. I then pushed her and she fell on the floor. My husband started yelling even more. 'You hurt your mother. Look what you have done' (IT 2, pg. 6).

My mother is about 85 years old and she is skinny. She said she was hurt so we called my brother. He brought her to the hospital. I have said sorry to my mother so many times. After that day she went to my brother's house. And then she went to India for the winter. She never came back to live with me after that day. I know it's because of what happened. I feel very sorry.

It makes me feel really sad not having her with me. I think that she is the only one in my family that loves me. She is the only one that understands me. I talk to her on the phone every day. But it's not the same. She cannot protect me anymore.

This was a sad moment for Harrah. She felt terrible as she felt she had caused this. That she was to blame for her mother leaving. Her confident and protector was gone. As time went on, Harrah has seen her mother less and less. Where she once saw her every day she is now seeing her every few months…

This and many other accumulated stressors have weighed down on Harrah.

'Sometimes I have the depressor {depression} for it and can't sleep at night. It's the big problem. And the problem is that I don't think my husband can stop. He went to the place for the gambling but it still a problem. And the kids they see that it makes me angry and we fight. That is another big problem. I don't want the kids to be placed. And I know that if we get the divorce because of my medication they won't give me the kids. That why I stressed' (IT 4, pg. 3).

What will happen next?

I don't know what will happen to me and my husband. He always tells me that he wants a divorce. That things would be easier for him if he moved to India. Sometimes we say that we are all going to move to India. His family still lives there.

There are no machines in India. So maybe we would have a better life there.

My husband sometimes he beats me. He beats me and I cry. He will usually hit me when he is not happy with me. He tells me that I don't do anything right. I tell him that he has made me this way.

We still fight a lot. Especially if he has been drinking or gambling. Or if the supper is not done. Or if I sleep too much. I tell him that it is the medication. He tells me that it's because I am lazy.

But one thing I know for sure is that I don't want to be separated from the children.

When youth protection closed our file the man he said that if they have to re-open it again that they will place the children. Forever. I don't want that to happen. That would be too painful for me. My children are 'the most important thing' (IT 4, pg. 4) in my life.

My money issues are also a big problem. If we would have done better with the money, maybe we would not be in this situation. Maybe we would not have all these bills to pay and no money to pay for them. Now we have the public curator that is managing our money. I don't want them to manage my money. It's my money. And I don't like not having control of my money. But they say that they can help us pay the bills and that it will give us less stress. I hope that happens. I don't want them to always 'magic {manage} my money'.

I don't think our money problems will ever change. I sometimes think that my husband also has depression. That is why he acts in those ways. With the gambling and drinking. But I am still mad at him. For taking the $15 000. For making me pay all the bills. For me having to take care of the children.

I want my children to have fewer problems than I have had. I want them to have more money than us and I want them to get good jobs. To go to school. I don't want them to go through what we went through with any of our problems. Maybe they will become doctors. I want them to have children and I want to be a grand-mother one day. Not right now, but when the kids they get older.

Harrah described the importance of her children.

"Children is very important in my culture. Without children 'I am nothing. That the woman has nothing" (IT 3, pg. 4).

My children are everything to me.

"What do you think, do you think it looks pretty papa?" Selia touches her braid." It looks pretty Selia". "See, that's what happens when she listens. She looks pretty" (LP, Reflective log, August 5th 2009).

4.2 Maria's Story

The stairs creaked as I walked up to Maria's apartment. Three more flights to go. Maria calls me from the 3rd floor. 'We are up here'. Her voice seems warm and friendly. As I approach the door, I am struck by the smell of fish, maybe sardines. Maria is standing at the door, waiting for me, with a smile on her face. She is a small woman, maybe 5 feet tall with a small frame. Short dark curls adorn her soft face. I shake her hand and she tells me that she has been waiting for me. I begin to take off my shoes (a social cue I took from all the shoes outside her door), she waves her hand in the air and says 'no, no, it's not raining outside keep them on'…. As I walk into her home, I see all of her family portraits displayed on the wall. Following my eyes, Maria says 'I love pictures. Must be from my mom'. 'This huge one in the middle is my parents before my father died. Beside them is my daughter at her 1st communion just before her accident. And that one is my son at his confirmation, in *the suit I bought for him. And that one, well you know who that is', as she points to Jesus in the painting of the last supper. (LP, reflective journal, IT 1, August 4th 2009).*

My family, my culture, my religion they are all a part of my story. My name is Maria I am a mother of two children; Mary 20 years old who has an intellectual disability and Manuel 19 years old. They both don't live with me right now, but I see them on the weekends. This is my story. This is our story.

Birth Story: The Miraculous little Doll

Fall 1958

When I hear the word story, it makes me think about my story. And I want to start my story from the beginning. I was born in a small farming village in Portugal. My family was poor. My father sometimes had to work two jobs in the village in order to support the family. But many families in my village had to do the same thing. We were not the only ones.

I am the youngest of two children. It's just me and my sister. I was born early: my mother was seven months pregnant when she gave birth to me.

This story, of my birth, would be a story that would become a part of my family. One that would be told over and over again. I would be known in my family and in the community as the 'miracle baby'.

When my mother gave birth to me, I was really small. 'They told my mother that I would not survive. I weighed only two kilos. Like a packet of sugar" (IT 1, pg.1). When my family heard that I was born early and I was so small they began to pray. They even put oil all over my body, and they believed that it was "in God's hands" (IT 1, pg. 1).

I almost died a few times in the hospital and my grandmother wanted to take me home. I remember her telling me years later saying that 'if she dies then I want her to die not on those machines but in my arms, in her home" (IT 1, pg. 1). My mother, my parents, my grandmother, they never left my side.

A month would go by.

And then it was like a miracle happened, I began to get better. My heart was beating faster. I didn't need those machines anymore. "It was the medication and the prayers I think. Everyone said it was a miracle. They use to say, I know she is the miracle baby, in Portuguese they used to say that…they used to say where is the beautiful little doll" (IT 1, pg. 2).

When I think about this story, I think that "it was meant for me to be here, they tried so hard to save my life even if the doctor did not want to. But everyone you know pushed… Today my mother says that I suffered so much, and everyone worked so hard to make me alive and your life is a miserable life" (IT 1, pg. 2).

This is the story that my family likes to tell about me the most. And this is the story that I like to hear the most about myself.

A love-hate relationship

I grew up in Portugal. And came to Canada when I was twelve years old. I remember that I had a good life with my family, that I was happy. When I turned 18, everything would change…

I met my first boyfriend. I saw him from my house, from the balcony. I was living in the Portuguese neighborhood in Montreal at the time. He was handsome. He had tattoos on his arms and drove a motorcycle. He was so cool. Our eyes met from across our balconies. I had a funny feeling take over me. He was also Portuguese but lived in the States. He was visiting his sister who lived next door to me at the time. The next thing I knew he was over at my house with his sister. He was asking my parents for their permission to go out with me.

You know the olden days, in the Portuguese culture; guys had to ask your parents to go out…. The guy has to prove to them that he has a good family, a hard worker, you know good reputation, good guy (IT 1, pg .6).

My parents said yes, but I think they had their doubts. They didn't like the way he dressed, they thought he looked too tough, too cool. We went out a few times with his sister before he went back to the United States. And for a while, we exchanged letters, cards and gifts. It was the first time that a guy liked me. It was the first time that a guy paid attention to me.

And I liked that attention.

After six months of dating

Then one day, he started calling me a lot. He started repeating himself all the time. I felt like something was wrong, like the guy was not normal. "I could tell in his voice that he was drinking". But what could I do? I couldn't tell him to stop. But I didn't like it.

After my nineteenth birthday, he wanted to get married. My parents wanted us to wait because my sister had just gotten married and they wanted to be able to give us a nice wedding too. But he still wanted to get married right away. I didn't want to marry him right away. It felt too soon.

Instead, he convinced my parents that I should go see him for a few weeks. I could go visit him with his sister. My parents made his sister promise that I would come back the way I left. They meant that I would still be a virgin. His sister promised that she would always be by my side. Because in my culture it is not right to have sex before marriage. It is considered a 'sin'.

Hell on Earth

When I got to the States, I would see the other side of him. A side that I wish I never saw.

I found out that he liked to drink a lot, hang out with his gang of motorcycle friends and take cocaine. He was not himself when he would do these things. But most of the time his family was around so I was ok.

Then one day, the family went to the beach. I was left alone with him. I could tell that he had been drinking. I could smell it on his breath. He told me that we were going to go down in the basement. I told him that I didn't want to. I didn't want to have sex with him right then and there; I wanted to wait until we were married.

But he forced me downstairs. He took my hand and pulled me down the stairs. The basement was full of dirt. There were many spiders on the ceiling. There were no windows. And it was really dark.

"And then he pushed me on the sand underneath the stairs in the basement and he was saying bad things to me like bitch, whore, and things like that. And I told him not to call me that, that I was not that. And he told me that he wanted to have sex with me and I told him that he was not going to touch me. But I couldn't do anything, he was stronger than me' (IT 2, pg. 5).

"He tore off my clothes and he took off his clothes, you know the way he made love to me, it was not love. It was like rape. He was on top of me and forcing himself on me, I told him to stop but he didn't care. He didn't stop. The more I told him to stop, it hurts, the stronger he got on me. He was on me. I was dying for him to stop. I was dying for someone to come home" (IT 2, pg. 5).

But they didn't. I ran to the bedroom upstairs when it was over. I put the chair against the door. I sat on the floor and just cried.

I couldn't believe he did that to me. I felt like an animal. And I felt dirty.

No one deserves to go through that.

And I didn't say a word about what happened while I was there. To anybody. Not even to his sister.

If I had stayed much longer in the States, I don't know if I would be here today. All of this was difficult to handle but I was also scared of my parent's reaction. I had this feeling that I was pregnant. That I would not be able to hide this from my parents. I was going home, no longer a virgin, and maybe pregnant.

The Portuguese people they are able to sense things without you having to say a word. "The old Portuguese people it's like they see it in your eyes, on your face". I would have to face my family. When we arrived and got out of the car, my parents saw me. My mother started crying and my grandmother started saying "that is not our Maria that left us, she is different, like a different person" (IT 2, pg.6).

I think that they could see it in my face. It was not supposed to happen this way. Not in a basement full of dirt. Not with 'an animal like him'.

Caught in the Middle

I was right. I was pregnant. My parents were not happy that he had gotten me pregnant. My mother told him that he would have to marry me after he had gotten me pregnant. "She said you come right now and you marry her. He said "I don't have to marry her. I already had my fun with her. For me it was like damn it, asshole, {excuse my language}, but he just wanted to use me for my body. Not interested in making a life with me, just to have me as a prostitute" (IT 2, pg. 7).

At this point I didn't want to marry him but I wanted to keep the baby. But my parents, my mother specifically, wanted me to have an abortion. ' So, uh, my mom made me have the abortion, I didn't want to have the abortion, but my mom made me, I wanted to keep my baby but people used to tell me that it was not a good idea' (IT 2, pg. 7).

I tried to stand up to them by telling them that I wanted to keep it no matter what. The abortion would be one the most difficult events in my life. I didn't want it to happen 'And that day, it was like a part of me was dead, a part of me died. It was my first kid, I love kids, I didn't want it to be that way. But, I guess my life had to be that way' (IT 2, pg. 8). 'I told my mom I wanted to keep it. It was a sin, because in our culture, no matter what you keep the baby. We're catholic you know. But my mom said this child was not made of love it was made of rape. It was not meant to be. I told her that if it was meant to be or not, I wanted to have it. I would love it no matter what. But the best thing they told me was to take it out' (IT 2, pg. 8).

I felt like I was stuck, like I had no choice.

Newlywed life: not a pretty picture

"They say that first love is supposed to be you know, feeling like the princess or the queen, but sometimes it is not… it's not always roses" (IT1, pg .11).

A few months after all this happened, we would get married. My mother told him to marry me. He took my virginity from me. That it was his duty to marry me. I think she was scared that I could not find a husband if I was not a virgin.

And our wedding night was not a fairytale. It was more like a nightmare. "And the night of our wedding day it was hell. He beat me and I stayed at my mom's place and they heard me screaming from the downstairs, but no one came. Not my mother, not my father, not my sister, not my brother in law. Not my sister's son. Nobody came downstairs. To break down the door' (IT 1, pg. 7).

My family just ignored the screams that came from downstairs. He was upset because I was speaking to some men at the reception. He knew that they were my cousins, but he didn't care. He even tore up some of the money that we had received because it was given to us from some of my male family members. Any excuse to rape and beat me.

The abuse would go on for months. Even when we moved out into our own apartment. "He tried to kill me with a knife. He used to beat me before having sex and tie me to the bed and then do what he wanted to me. I was like a puppy or an animal, he used to have sex with me and punch me and then when he had enough, he would fall asleep. And I couldn't move, I was still tied up. I used to yell and scream and no one would help me' (IT 1, pg.8). My family seemed to drop from the face of the earth.

'My family ignored me. I used to see them on the street, and they pretended they didn't see me. It was awful. I didn't see my mom anymore, it was like I never existed' (IT 1, pg.8). I really wanted my mother to save me and protect me from him" (IT 1, pg.10).

I really felt abandoned by my family. By my mother in particular. " I know she tried to save my life when I was small and with all of this that happened, it's like I do not have any value for them anymore. Like I really don't know what love from a mother is. From a father, yes. But a mother no. Because for my mom, any mistake we make, it's a sin, you know. The Portuguese way. That's the culture. People think it's your fault. And everyone used to tell my parents that I was going through hell, and they didn't care, they just pretended they didn't hear" (IT 1, pg. 9).

After a year of dealing with the abuse, I'd had enough. I told my sister, at work, that I couldn't take it anymore, that I couldn't take the abuse. She helped me to get out of it. My mother didn't want me to come back home. She said "she is where she wants to be". My grandmother also talked to me and my parents "She said please come home, you don't deserve what you have been going through. Your parents made a big mistake.

Forcing you to marry him just because you said you were pregnant. And my grandmother told my mom 'go and get your daughter, for your father's sake" (IT 4, pg. 5).

I ended up moving back with my parents and getting a divorce. He would get deported to the United States. He tried to come and see me afterwards, before he had to go back. But I called the cops. I told him to leave me alone. And for the most part, he did.

Until death do us part

I lived with my parents for six years before I met my second husband. It was another traditional courtship. He was the brother of the neighbor. His family and my family knew each other even in Portugal. We were from the same island. The same village. His sister thought that we could be good together. So she introduced us.

When I first saw him, I really didn't like what I saw. He was short. He looked old. And he wore old fashioned clothes. He was also twelve years older than me. My mom thought it was a good idea for us to go out. He was older and maybe he would be more mature. It was not possible that this guy could be any worse than my first husband. I was encouraged by my family to at least give him a chance.

And I did.

We would go out with his sister on Wednesdays and Sundays like they did in Portugal. We dated for a year. I didn't have strong feelings for him. For the first one I did, but for this one I did not feel very romantic towards him. After about one year, I started to see his ways. He would go out until 2-3 in the morning and sometimes I didn't know where he was. "And I used to tell him that I am not his ex-wife and if he wants something with me than he has to stop doing this" (IT 2, pg. 4).

I would also tell my mother that I didn't like what he was doing but she told me to keep going.

At least he was not hitting me.

I kept going. After about two years, we got married- civil. I couldn't get married in the church because I was divorced. So was he. "And when we got married that day he was grumpy not a smile on his face and I was not happy myself. But I guess I thought to myself I felt stuck and there is no way out' (IT 2, pg. 4).

I didn't want to disappoint my family or my in laws by not marrying him. So I did. When we first got married, he was ok. He wouldn't go out as much. He would not drink very much. He was nice. I thought that maybe I could love him. But then he started going out again. Telling me he was going to the store to buy bread and then not coming back until 3 in the morning. Again I would talk to my family about it "And at the beginning no one believed me that he used to go out and leave me alone, they used to say stop making such a big deal of it, my sister's husband used to do it too and just basically they wanted me to live with it" (IT 2, pg. 5).

The Best Day of my Life

I always wanted to have children. My husband didn't want any more children. He already had two girls from his first marriage and hardly saw his kids. They never called him. And he didn't call them either. But I held on to my wish to have children especially as "I always wished for a little girl, especially for the first time". Within the first few months of marriage, I would become pregnant.

I was so happy. My family was also really happy. My husband had no reaction. I could not tell if my husband was happy or sad. It was no surprise that he did not come to any of the appointments for the baby.

My parents came with me to the ultra-sound and I told them not tell me the sex of my baby. I wanted it to be a surprise. Even though in my heart I knew that it was a girl.

A few weeks after I found out that I was pregnant, my sister also announced that she was pregnant. For the first time in my life I felt close to my sister. It was a happy time for my whole family. My sister and I even tried to get our appointments on the same day so that we could all go as a family. I really felt that I was a part of the family at that time.

My pregnancy did have some complications. One day while I was at work, I began to bleed. They had to take me to the hospital. I was so scared that I had lost the baby. That something terrible had happened. When I saw the doctor, he said that the baby was fine but that I was going through too much stress, that work was causing too much stress. So he told me that I would have to go on bed rest. I would do anything to make sure that my baby was ok. My husband was not very happy that I had to stop working. He seemed angry that he would have to bring in all the money. He also did not help me while I was at home. My mother and his family would come over to make sure that I was not doing things around the house.

I really liked being pregnant especially when things were going well. It was really an amazing feeling. And I would often think … "How could this thing be in me, it is like a miracle to me. A human person growing inside another human person. Another human being and you are the one feeding this human person and you will give birth to them, like it happened to you. Like for me it's a real miracle and something I wish every woman could go through it" (IT 2, pg. 7).

I moved in with my parents after seven months of being pregnant. I began to question, what if my water broke and my husband was at a bar? I might be on my own. My parents were the ones to suggest it to me.

And then one night in the ninth month, I began to feel a really strong pain in my stomach. And then a gush of water came out. I woke up my parents almost screaming. My mother called my husband to hurry and get to the hospital because the baby was on the way.

The pain at this point was stronger than anything. I felt these cramps that were getting stronger and stronger. I knew that the baby would be coming out soon. The next thing I know was that I was giving birth. "I heard him cut the cord and then the pain stop. I didn't see my husband's face at all during the birth and after I didn't know if he was happy or sad. And then they out her on time all dirty but it was nice, it smelt so nice. It smelt like the skin of the baby. Tears were running down my face. And then she started to cry because the doctor tapped her on her bum. She was so small, fragile, so peachy, so rosy. With brown hair. It was so cute, you know. I don't know how to explain it, but it was the best day of my life. The best day of my life. It was the best day that I ever had' (IT 2, pg.8).

Even though I didn't feel my husband's presence when I was giving birth, it was not about him. It was about me and my baby. "The hell with him, I had my daughter." In my eyes, my daughter was 'the best gift I have ever had. Even though my marriage had no love. But Mary she gave me the love that my husband didn't. And I guess I gave her the love that her father never gave her" (IT 2, pg. 7).

Mary had jaundice after she was born and she had to stay in the hospital for a few more weeks. I didn't want to leave the hospital without her, but I had no choice. I wanted her to get better, but I didn't want to be separated from my little girl.

I remember that day when I brought Mary home from the hospital. I was so happy yet scared. I knew that my husband would not help me and that I would have to do a lot of it on my own. But I didn't have to do it on my own. My mother would come over every day and my mother in law would come over as well. I was happy to have this support. My husband was not around a lot. He was either working or out drinking. 'And he was never there. He never changed a diaper. Never helped feed her. Oh, he gave her some cereal when she was one years old, which is all he ever did for my daughter' (IT 2, pg. 9).

It seemed as though he was more annoyed with Mary than anything. She used to cry in the middle of the night and he would scream at me. I would tell him that this is what baby's do.

One night when he came home and he was trying to fall asleep, Mary started to cry. He told me that if I didn't find a way to keep her quite then he would. I was rocking her in my arms and he came towards me. He then grabbed Mary and threw her. Her head ended up hitting the bed board.

She stopped crying.

Mary was rushed to the hospital. We told them that she fell from my arms. And they believed us.

She was hospitalized and had a brain damage as a result.

It would be something that I would never forgive him for. I didn't tell my whole family for years. My parents told me to keep it between us. They didn't want anybody to think badly about us.

About a year later, I gave birth to my son, Manuel. My husband was much more involved in my pregnancy and with the birth of my son. He even gave cigars to our family when my son was born. He even picked him up and played with him, which he never did with my daughter. That always bothered me because both of my children were equal. 'Because if it's a boy or girl, you should treat it with love. Maybe it's also because of Mary's handicap. She has a brain handicap, kind of like me but much worse. And I don't think he liked it very much' (IT 2, pg. 10).

Because of Mary's handicap, I spent more time with her. I would take her to the therapies. My husband never believed in these therapies. He would say that in Portugal, these things did not exist and therefore he did not believe in them.

The Last Straw

I could never forget what he did to Mary. When he hurt her, he hurt me too. As the kids got older, he drank more. I knew that I could never count on him. It was difficult for me to get the kids to listen to me and he would usually scream at me for not getting them to listen. I wanted to leave him. I wanted to get a divorce.

But I had a feeling that my family would not be on my side. I knew that they would not support me in getting a divorce.

'So my family was not happy about it about me leaving him because they said that marriage is like until death do you part you know what I mean. Yeah, but I couldn't handle it no more, too much stress and he didn't behave the way he was supposed to behave" (IT 4, pg. 1) 'But my mother she said ahh, for richer or poorer like they say in the church, but I like I told my mom, that's old fashion, you know.."(IT 4, pg.3).

My parents told me to give it one last try. So we went for couple's therapy. He went with me at the beginning and then stopped going. I was really miserable and wondered if this was the way it had to be. "What is the use of having a life like that?"(IT 4, pg .3). I also questioned my parent's values in relation to marriage and the notion of death do us part "If he was a good man, ok you keep him forever. But if once in a while he is like an animal or violent or beats you kid for nothing or for anything, and yells and screams at you. Or goes out all night or stays out for a few nights. You don't even know if he is dead or alive and your alone with the kids looking at your watch, waiting to see if the door opens or the phone will ring. It gets kind of stressful, angry and it makes you upset. And you can think the worse, like something happened to him. Maybe an accident or something, maybe he is dead. You never know what can happen when they are not there all day. But you have to go to sleep because how are you going to take care of the kids?"(IT 4, pg. 2). That's why I needed to leave. To make a better life. For my kids.

It was at this point that I had asked for a divorce.

Alone with the Kids

Though I was in an unhappy marriage, it was still difficult to leave my husband. It was hard because I have never been alone. Not with the kids. Not even when I wasn't married. I lived with my parents.

After my divorce, my family and his family disappeared. I felt alone.

I began feeling very sad and had difficulty taking care of myself. The doctor's said that I was having a "nervous breakdown". Taking care of the kids was difficult during this time. I spoke to my social worker at the community center and she organized a meeting with my whole family. My parents, sister and a friend attended this meeting. The workers asked if my parents would allow us to stay with them "Well all my family said no at the meeting. I felt even worse. My parents didn't accept me and the kids and my sister she was working nights. I understood that' (IT 4, pg. 2). A friend of a friend that I had met at a women's shelter said that I could move in with her and the kids. This would give me some rest while keeping the kids with me. At the beginning, I was happy that I was staying with Nicola. She would make the meals and take care of the house while I was getting help and taking care of the kids. She also encouraged me to go home and get a few hours rest.

After being at Nicola's for a few weeks, I went home and spent the night at the house, while the kids stayed with her. I knew that this would be more difficult for my daughter as she has never been separated from me. I explained to her that I would be gone only for one night.

That night I would get a call in the middle of the night. It was Nicola, there was an accident with Mary. She had jumped out of her bedroom window and landed on the ground. She was lying in a pool of blood. She had called the ambulance and told me to meet them at the hospital. I was so scared.

I didn't know if my daughter was dead or alive (IT 3, pg.4).

I rushed to the hospital. When I got to the hospital, they told me to go see her right away. She was calling for me. "I saw her face, I didn't recognize her face. And uh, they took off her clothes it was full of blood. That's all I saw, it scared me half to death" (IT 3, pg. 4).

I saw Nicola, and I didn't know what to say to her. "And I told her damn it, what happened, didn't you watch her, didn't you lock all the doors?"(IT 3, pg.4).

The doctor came to talk to me. He said things so fast that I couldn't really understand what he was saying. And then my mom and sister finally came.

The doctor told us that Mary had a broken nose, jaw, leg and some of the vessels in her eyes were broken. They told me that she would need to have some operations and stay in the hospital for a long time.

I stayed by my daughter's side for most of the time. Sometimes I would go home and then they would call me as soon as she would get up so that I could go to the hospital. This was a difficult time for me, not only because my daughter was in the hospital, but because I felt so alone.

But I did this all for Mary. "I don't know where I got all that energy, I don't know where I got all that strength, but I had no choice, I had to be there for her. There was nobody else" (IT 3, pg. 6).

I brought her a doll that I had bought her when she was three years old so that she can sleep with it when I wasn't there. I hoped that this would comfort her as she would have something from home with her at the hospital. She smiled when she saw the doll and kept it close to her on the bed.

When I think about that day, I still don't know what happened. And today Mary still has a problem with her leg. It might have also caused some more brain damage.

After my daughter's fall, it was really difficult to manage things with the kids. I had not regained my strength. I had another meeting with the workers and they thought that things were not going well.

Things were not going well.

Mary was 12 and Manuel was 11 at the time. I had no energy to make them food and to get them to listen to me. I felt like things were out of control with the children and I had no idea how to get things back in order.

The workers made the decision that the children would have to be placed. I felt like maybe if I had more support from my family that I would be ok. 'But I had nobody to help. It's like I had lost everybody and have no one to turn to' (IT 4, pg. 7).

Mary was placed in home where everyone has a disability. While Manuel was placed in home with youth protection.

I really felt sad about the kids leaving. I wish that they could have stayed with me but maybe if they did none of us would be here today. It was really hard not to have them with me anymore. It was really painful at the beginning.

'It's like house is so empty, it's like every time I used to look in my daughters room I used to cry. Every time I used to see her toys hanging around, sometimes I used to sleep with them, they didn't replace her but I just felt kind of safe I didn't feel so alone' (IT 4, pg.6). I use to also take turns sleeping in their rooms at night, in their bed. I could almost sense them being there.

It was also a really hard time because of the things my family would say. They would tell me that I was a bad mother. This would make me feel like a bad mother. 'No matter if you keep them or replace them for the better for them and the better for you, people will talk. They will always pick on you on your kids, behind your back. Sometimes I feel like punching people, to tell them to shut up. But sometimes you don't have the courage to do that' (IT 4, pg. 7).

I did get the courage to do stand up to my cousin once. I was visiting my aunt who was very sick in the hospital. My cousin began asking me why my life was such a mess, why I couldn't even take care of my children. I spoke up to her "And I had enough, you know, they would always talk about it me and just couldn't take it. So in the hospital in the hall I screamed, I am mentally retarded, I am fucking mentally retarded, what don't you understand about that! I was just tired of that. She didn't say anything else after that, she knew that I was fedded up" (IT 4, pg. 7). Sometimes that's why "I hate being Portuguese. Your business is everybody's business. But they don't know until they walk in your shoes. Then maybe they will shut their mouths!" (IT 3, pg.9).

All of this 'is like a bad dream'. "Sometimes I feel like it is all my fault". And sometimes I think it's really bad luck.

Children growing up and the future

I can't believe that my children grew up so fast. I wish that things could have been different. That my children were still with me. That my situation, their situation could have been different. I wish that they didn't have to go through so much because of my life. "I hope that they forgive me one day. I hope they know that I wanted them to have a better life. A better life than me" (IT 4, pg .9).

With my daughter, I know that things are different. But I know that she also wants to be like other girls her age. She is growing up. "I know that my daughter likes babies a lot and says she wants to have a wedding. You know she has her own dreams you know" (IT 4, pg. 4). But I am not sure she will ever have her own family. She has to be with people all the time. She can never really be left alone. She will always have to have someone by her side. I am also afraid when I hear her talking about boys that something bad will happen. That she might be hurt again. That someone will take advantage of her. Like the janitor did.

When Mary was 8 years old and attended a special school, she was molested by a janitor at the school. Mary had disclosed this to Maria who immediately reported it to the school. It took many weeks of advocating and pushing from Maria's part before they took the allegations seriously. After further investigation, many children came forward and the janitor was fired and legal proceedings were undertaken.

Even though my daughter does not live with me, I worry about her all the time. I know that Pauline takes good care of her. Pauline is my daughter's caregiver. But sometimes I know that she does not like when I ask her questions. Like when I ask her about birth control. When I ask her these questions, she thinks that I don't appreciate what she does for my daughter. But that's not true. I just worry about her because of what happened in the past.

Sometimes I feel sorry for my daughter. She has asked me why she is the way she is. And I tell her about all the things that she is good at. Like, she does great paintings, chooses really good colors. I also tell her that she is very pretty and she is also really good at sports.

I also worry for my son. I worry that he was affected by being in placement. He has told me that it is my entire fault. That I did this because I don't love him. Sometimes he will say to me "are you stupid? Are you crazy or mentally retarded?" I tell him not to talk to me this way. But, I think he is still angry with me. He has told me 'that I have let him down when I let him go" (IT 5, pg. 6).

Manuel wants to move in with me after he leaves his home. A part of me wants him to come back and the other part of me is scared. I know that when he lived with me he was really controlling, like a second husband. He would tell me what to wear and who I should speak to. But maybe if he moved back with me he would think that I loved him. And maybe I wouldn't feel so bad for having the children placed.

Having a disability in the Portuguese culture is hard. "It's a sad thing for a parent to accept, to see and to belief" (IT 7, pg. 1). It makes family's believe that they have done something wrong. That's why many people will hide the fact that they have a disability. You don't want to be bad in the Portuguese community. Because that makes people talk. That marks your family as bad.

I don't even understand my disability. Like what does it mean? What happens to me? "Because they say that I have a handicap… and that makes me want to disappear" (IT 7, pg. 6).

I think that there were some difficult things that happened in my life, with my children. "Sometimes I wonder why all these things happen to me. Some people say that it's because God thinks you can do it. I don't know. I think it was enough with all that happened with my kids" (IT 3, pg. 10) "A lot of things are hard. But you know what they say. You know the Portuguese with the religion; God only gives you what you could handle. That's what my grandma used to tell me" (IT 3, pg. 10).

I want more than anything for my children to be happy. That is what I wish for them. They don't have to get married and have children. They don't even have to marry someone who is Portuguese. All I want for them is to "… have a good life and not suffer like me. Or worse than me. They don't deserve it. I just want them to have a better life then me" (IT 4, pg. 4).

I hope that they are always happy and safe, even when I am no longer here. My children are the most important thing in my life. "They are the only thing that keeps me in this world. If it wasn't for them, I wouldn't always want to be there. I thank for god that I have them" (IT 2, pg. 13).

The doll that my daughter always carried with her is still with me. It's in my room on top of my bed. I guess it always reminds me of my precious little dolls.

4.3 Halina's Story

I am angry. Things just did not turn out the way I thought they would.

When I was younger, I didn't want children… But then I got pregnant, not once but twice. Then I pictured myself with about 35 of them. A big happy family. That's what I had imagined, but that's not what happened.

I met my husband who drank a lot. When he drank, everything fell apart. I blame him for tearing our family apart. I blame him for hurting the children. I have two children Tracey who is 19 years old and Michael who is 11 years old. They both have special needs. I am the one that has been their mother and father. How do you think that being a single mother, with a learning problem and two children with disabilities look to my polish community? To my family?

And then people wonder why I am so angry…

Before I talk about how and why my anger started, I want to talk about what is most important to me, my children and being a mom to them…

On Being a Mom Today

Being a mother, is a great thing, but I am not going to lie, being a mother hasn't always been easy. We have gone through a lot as a family, but today we can say that we are still together, at least me and my children are.

I am a single mother to my two children. And trust me this has not been a picnic.

"Its' very tough being a mom, it is the hardest job today. Trying to support my children. And not getting any support from the father. Trying to pay all the bills, from the lunch program, school, rent, bills. It's really tough to do everything on my own when you have no partner to help you out" (It 1, pg. 3).

On top of being a single mom, there are things that I need to do, that moms in my culture need to do to be seen as a good mother.

"Moms in my culture are the ones that take care of their husbands, their children, the housework, groceries and take care of the kids. Make sure they have their baths and shower. Get then up in the morning, make sure they eat well in the morning, get them to the bus in the morning. It's not that easy" (IT 1, pg. 2).

Being a single mother is not something that is seen in very good light in my community. It bothered me at the beginning, when I first got divorced, but after that I said

"The hell with them! They say all these bad things, but where are they when I need to give my son a bath? Where are they when I am making lunch?" (IT 2, pg. 5).

So instead of listening to what people say, I focus on what I have to do for my kids.

I have a busy schedule and most of it has to do with things that I do for my children.

I wake up early to make sure that my children are both ready for school. I make their lunches. I wait for my daughter's adapted transport and walk my son to his school. I then make supper, clean the house and go get my son from school. Once they get home its homework, supper and then TV. time. "I always have to be one step before my kids" (IT 1, pg. 2). Otherwise it can get out of hand. I can get too disorganized. And both my children need organization.

I have learned a lot in the past 19 years that I have been a mother.

"It's really important not to yell at the child. As the baby gets older, you don't yell at them. Um, take care of the baby and make sure that the baby has food and clothing for newborns. It's important to give them a lot of love. Give the child love and be there if they need you if they run into a lot or problems, give them the advice. Um, if the child has homework for school help the child out, if the child has a problem and they can't do it you need to help them out "(It 1, pg.5).

Both my children are handfuls.

My daughter is always getting into trouble with her stupid friends. I think she chooses friends that are no good for her. You see because of her handicap she trusts people too easily. Children with handicaps also have to be more careful, because there are some bad people out there. Like the driver of the adapted transport that touched Tracey. If I could I would strangle him! This happened about one year ago. We are waiting the court date. Someone will have to hold me down if I see his face in court. "How dare he touch my daughter? How dare he touch a girl with handicaps!" (IT 2, pg. 6).

And people wonder why I am so angry.

The other problem is that my daughter does not think that she is handicapped "But her mentality she is about 14, her state of mind you know. Because she doesn't think the way she is, because she doesn't think like well she is way behind" (IT 3, pg.3).

I try to speak to her about it. But she just thinks I am being too strict. I am trying to help her because I don't want her to get into trouble. And I don't want her to get hurt.

But I remember too when I was young. I didn't want to admit that I had learning problems either. Because when you say you have a disability people look at you differently, they might even treat you differently. I know because it happened to me…

My son also gets into trouble. He has flushed toys down the toilet. This caused a flood in the bathroom. He has also pulled the fire alarm in the building. I think he has a hard time understanding what is good and what is bad. He still gets punished, but I wonder if it's sometimes because of his handicaps that he acts this way…

I only found out that my son had a disability when he was 9 years old, about two years ago. I thought that he had some difficulty learning but I didn't think he had a disability. The school had asked that my son get more testing because he was having a hard time in school. The teachers told me that he was not at the same level as the other children.

The school sent me to the hospital downtown for some testing. After a few meetings with the doctors, they told me that my son had a disability. That he had the same thing as my daughter and I. I was a little bit upset about that as I thought that my son would be ok. That he would be the one in our family that would be ok.

Having children with special needs is a "challenge". My daughter, she wants to be grown up, but it can't be that way. She wants to be more free. Maybe live on her own. But she has a learning problems like me. But more severe. I don't think she will ever be able to live on her own. I think that living on her own would be too difficult.

Maybe that would also be too difficult for me.

Having my children with me is my life. It would be too hard if they were away from me. Watching them grow up, makes me feel sad. I feel like I am losing them… And this is really hard because "My children are the most important thing. "They keep me going, they keep me alive" (It 2, pg. 4).

That's why when I think about the past and I think about what almost happened, when I almost lost my children to youth protection, it makes me so upset. Youth protection almost took them away about 10 years ago. It was the most difficult thing that I ever had to deal with. It was more because of what happened with my ex-husband...

Let me start that story, on how I met my husband, from the beginning…

Getting married and having children

I met John when I was 26 years old. I was still living at home. I met him at a bar near my house. I was with my friend and he asked me what I was drinking. We exchanged phone numbers and he called me the next day. At the beginning, we would go out together. We would have fun together.

Then after about 6 months, John would drink so much that it was no longer fun. When he would get drunk, he would always start a fight with me. And when I was drinking, I would fight back.

At this point I already started to think why I was with him… His drinking was a problem. My parents were not too happy that he was not Polish. Even worse, he was Arab. They also did not like that he was taking me drinking. The bars, was "no place to take a woman" (IT 2, pg. 8), according to my old fashioned parents. They didn't try and break us up, but they were not happy that we were together!

I stayed with him, because he was my first real boyfriend. And I don't think I wanted to be alone.

After about one year of being together, I was at work and I was feeling very tired and sick. My boss could tell that I was not feeling well. She asked me what was wrong. I told her what I was feeling like. She looked at me and said "you're pregnant, go to the doctor's right away" (IT 2, pg. 9).

That is when I found out I was pregnant. I was sixth months pregnant and didn't even know it! I didn't feel different except for being tired and cried a lot, but I thought it was because of the fighting with John. I knew even at that point that I was in it alone. Because even then "his drink was more important than anyone" (IT 2, pg. 9).

I didn't really know what to do.

John was an alcoholic and could not help me, and my parents wanted me to marry him because in our religion and culture that's what you do. "For the women, and I was the only one, I had to be getting married before leaving. They were not too thrilled when I told them that I was moving out, pregnant. They told my boyfriend that he needed to marry me. So he proposed" (IT 1, pg. 6). I knew even then that he would be a lousy husband and father. But I wanted my daughter anyway.

I didn't have a lot of time to plan for my daughter. I had to ask my family to help me out. I didn't like that. I wanted to do it on my own. My family wanted to help. Family in our culture usually help when children are born. They are usually always around. From the time the children are born until they grow up. That's the way it is. Family is supposed to always be there.

But I was different; I wanted to show them that I could do it. That I could do it on my own.

If I asked them for help that meant to me that I couldn't do it. And I wanted to this more than anything.

Before I knew it, I was giving birth to my daughter. "I was very nervous. I didn't have any help with any of that! And Tracy she was a 45 minute baby, she was such a quick baby. She wanted to get out quick, I guess! One minute you have her and then the next minute she popped out! And I was scared, I was so scared, because being a mother for the first time is really scary! What I'm I supposed to do with this kid? Just wasn't planned!" (It 2, pg. 3).

It was tough to take my daughter home from the hospital. I took me five or six months before I felt like I was good at being a mom. And the formula was tricky for me. I couldn't figure out how much formula she needed. I thought she was gaining weight, but she was losing weight! It wasn't until she was weighed that I found out what was happening. The nurse from the community clinic came to my house and told me that my daughter was not gaining weight.

And my mother was no help in this situation. "My mother would give me shit. She would say that you are not doing the thing right! Because it is supposed to be half formula and half water to dilute it. But I didn't understand that! I would have somebody to come in and talking to me but talking is cheap" (IT 2, pg. 7)!

I really wanted someone to show me. Step by step, instead of just saying what you are supposed to do. The nurse would come and talk to my husband and then he would try and show me. So he helped me out a little bit, especially after the woman would come. But he only did that for a little while.

But I still I felt like "there was nobody to help me" (IT 3, pg. 3). I didn't feel like my family wanted to help me. I just felt like they wanted to blame me when things were going wrong.

My husband was not very involved with my daughter. He was either drinking or watching T.V. John would often ask me to get out of the bedroom with Tracey when she was crying. I would go on the couch with her, but we would not get much sleep. The couch was old and failing apart and the spring would dig into my back.

As my daughter got older, it didn't get any better. I was doing it all. I would take her to school. Take her to the doctor. I would make the lunches and suppers. I would yell at John "to get off his lazy ass!" (IT 2, pg. 7), but that didn't help either.

Nothing changed.

It was like I was a single mother. Like I was "the father and mother" (IT 3, pg.2).

I still stayed with John. I didn't really talk to anyone about what was going on. And nobody asked any questions.

After 7 years with my daughter, my son was born. I was happy when I found out it was a boy because now I would have a boy and a girl.

When my son came along, I was able to use the skills that I had learned with my daughter. I was also able to learn from my mistakes with my daughter! I was now able to give him formula and knew how to hold him properly. John was also more helpful with my son. I think that is because in his Arab culture, men and boys are more important. "Boys have more value" (It 2, pg. 4).

Even though John was a little bit more helpful with my son, I still wanted him to be more involved. To help me out with the kids during the day. After all, he was hardly working. I tried asking him so many times to stop drinking. To stop drinking to be with his family, but it never worked. "His mother would tell him to be a man, they are Arab people and she would say be a man and take care of your family, but he wouldn't listen to anybody" (IT 2, pg. 4).

Nothing seemed to work. He could not hold down a job. I worked as a house cleaner for our family to survive. I cleaned 5 different houses. In turn, John was supposed to watch the kids; my son all day and my daughter when she came home from school.

One day I came home from one of my cleaning jobs and the neighbour saw me. She told me that John had locked the kids in the bedroom to go get some booze from the store. She heard the children knocking at the bedroom door. He had stopped to drink his booze and then came home. I was so angry. I was so upset that he would leave our children alone to get his booze. For them to fend for themselves. The children were only 3 and 11 years old at the time.

And people wonder why I am angry.

I was thinking, what would have happened if something went wrong when they were left alone! And I thought was this the only time that he did this?

He left them there, “locked in a room, like animals” (IT 3, pg. 7). I wish that I could have done that to him, to show him what that was like for them!

I knew that things were bad but now it was out of hand. This was when I thought, that it was not a good thing to stay married to John. It wasn’t good for anyone.

The Crisis

Just when I thought that things could not get any worse, they did. In 2002, the crisis happened. The children were 4 and 12 years old.

It started when I thought that John was paying all the bills. I would give him the money and he would pay some of the bills, including the rent. And then I got an eviction notice from the rental board. John had not paid the rent for several months. And then they told us that we had a month before they were going to kick us out.

There was nothing that I could do. It was too late and we had no money left.

No one wanted to take us in. Not my family or his. So I ended up in a woman’s shelter with the children.

I hated it there, but at least I was with the children. After a few days of being there, someone called youth protection. A worker came to see us. She told me that this was no place for my children. And I told them “if I had a choice, do you think that I would be here?” (IT 3, pg. 5).

I then I had to move in with my parents.

My daughter stayed with me and my son had to go to a group home. There was not enough room for all of us. My husband got the best deal; he went to live with his parents where he was well taken care of.

My daughter stayed with me and my parents for two months. My son stayed at the group home for 3 months. Youth protection wanted to make sure that things were stable before my son came back home. But I wasn't the unstable one.

This was a really bad time for me and the kids. At that time, I thought "Should I stay with this loser?" (IT 3, pg .6). Or should I try and make a better life for me and my children. My husband wanted us to stay together. He wanted to have his fun. But none of this was fun.

All of this was really stressful. I had to find an apartment, was separated from my son and had youth protection in my life.

Having youth protection in my life was probably one of the biggest stressors. "I had felt like I had a big bolder on my back. Until these people leave. I didn't want them to threaten to take my kids away. They would say that I was not a good mother. I was going through a lot of shit, I didn't know where we were going to live, so I had a lot of stress, my ex-husband that was the problem, but they made me feels like it was me, it was all my fault that my family had no apartment. I will never trust them, they are goddamned liars" (IT 3, pg. 7).

Everything felt like it was out of my control. I felt trapped. I felt like I was in hell. I also thought about taking my own life "I just couldn't take it no more. But then I thought about the kids and they are all that I had and I knew that they would not have a mother and that is no life for them. For what a stupid alcoholic of a husband and father? He already ruined our lives" (IT 1 pg. 4).

I was not happy about what was happening with my family. My husband was not a very big help. "The booze takes over everything and they just don't care about anyone, and not even their kids" (It 1, pg.3). If he didn't care about us, if he was never there, than what is the point? I had made my decision, I was going to leave him. I had to keep it from my mom because I knew that she was not going to be happy. “Marriage and God is really important and divorce is like a not something you do” (IT 1, pg. 4).

I did not want to disappoint my family, but I knew this was not good for my children. Again, I felt stuck. But I chose my children.

Getting back on my feet

It took a while for things to get back to normal. For things to be more stable. The first thing I needed to do was get an apartment. And I did find one. It was close to the old neighborhood so the kids would not have to change schools.

Believe it or not my children missed their father. It really used to drive me crazy! How could they want to see that man? “he put us through so much shit!” (IT 1, pg.6). But he is their father.

The children heard and saw a lot when me and their father were together. “I am sure that they heard us fighting and when he used to drink he used to talk louder and say stupid things. They also saw me worry and wonder where the hell he was. I tried to keep them away from all of this but sometimes John made it impossible” (IT 2, pg. 6).

I feel badly for my children, that they had to see all of that. But it took the crisis for me to leave him.

After a year of being in my new apartment, youth protection closed the file. It was one of the best days ever!

Being alone, I was also able to make all the decisions in the house. I was really able to be their mother without anybody stepping in the way. Not my ex-husband, not my mother and not the Department of Youth Protection (DYP). My husband could be very strict with the children when he was around. I wanted them to listen to me “no children of mine will be bad mouthing me!” I decided that I was not going to work outside the home, the children “need me more now” (IT2, pg. 6).

So I stopped cleaning houses. I just focused on taking care of my children. To make sure that they were happy and safe.

The children still get to see their father. "Even today, the kids see him and I have to bring them down to them, he is too lazy to visit with us. I don't think that he deserves to see the kids but that's not what the DYP decided. Even though he is a boozer, he still gets to see the kids. How is that fair? He put us all through hell and he still gets to see his kids. I makes none sense to me. And especially now that the kids are growing older, they influenced more you know, they know what is going on and they know what happened" (It 3, pg.3).

Sometimes the children will go and see their father in his home. We take two busses to get there. Or he will come to see them at my apartment, but I tell him not to bring his booze. I don't drink anymore and I don't want the children to see their father like that. If he wants to drink in his spare time, he can go right ahead! But not in front of my children!

I also came to realize that I could not do this on my own. I needed to have some support. The most important support is the support that I receive for my parenting and my anger. "By talking about issues, by letting the problems out instead of me bottling it up inside. By doing that I think it really helps me by doing that the temptation to lash out is not as bad" (IT 3, pg. 2).

It helped me to learn that my anger was covering up other things.

When my anger started

They tell me that my anger comes from somewhere. That it is also something that happened when I was younger. I think this anger might have started when I was growing up.

I was born in Montreal and had three brothers. The only girl. My family came from Poland. We participated in polish activities at the community center. My mother always cooked polish food and we sometimes went to the polish church.

Things were really strict growing up. I remember this one time when both my brother and me were punished. We had left our house without asking my mom for permission.

When we came back home, my parents were waiting for us in the living room. They both looked so mad. They sent us to our room right away.

We had to kneel for two straight hours for seven days. I remember thinking when I have children, I will not do this to them. I will not punish them like this. But I think that it is a part of my culture; my dad was taught by his parents and they passed it on to us. But I would do things differently!

There was another time when my father told me he would break my legs. I was coming back from a field trip with school. My brother was supposed to pick me up and I waited. It felt like a really long time. So I had enough with the waiting. This guy in a car that looked like my brother's asked me if I wanted a lift. I went in the car and he drove me home. When we got home, my parents were by the window. My father said that if I ever do that again he would break my legs he "verbally exploded".

"We were taught that you need to respect. Respect adults, or else you were in big trouble. And sometimes I used to be scared of my dad, but I knew that I had to behave. I think that's why I am the way that I am with the kids. If you give them the room, they will not listen. They must listen or sometimes you can be a trouble maker" (IT 1, pg. 5).

It was difficult for me to be the only girl. Like I said, I had three brothers. And on top of it I was the only one with a learning problem. So I felt a little weird, a little different.

I knew that I went to a special class. I knew that my brothers didn't. My family they probably didn't want to treat me differently, but they did. I felt different growing up. I felt like I was not able to do the same things like my brothers because of being a girl and having a learning problem. In my family and culture you hide your disability. But I still I felt different in my family and at school. "I just had a very difficult time. I felt stupid a lot of the time and some of the other kids would say stuff to me" (IT 3, pg. 6).

I felt that the teacher too had something against me. There was my math teacher that slammed his hand on my desk because I didn't understand what he was saying. I just couldn't understand what he was saying! I jumped three feet high when he did that. I still remember the sound on my desk. I still remember how I felt. I felt small like I couldn't learn anything properly. I felt really bad about that. "Sometimes I used to think why was I born? I should never existed " (It 2, pg. 8).

I felt like something was wrong with me. Like, I didn't belong. And that is a very lonely feeling. Especially since no one in my family knew what it was like. "They didn't know what it is like to be like me. I mean they didn't know what it is like to have a disability" (IT 1, pg.9).

Growing up, no one ever talked about me being a mom and having kids.

"I didn't know where kids came from. No one taught me the facts of life, about the birds and the bees. Not my mom or the damn teachers" (IT 1, pg. 7 line 1). My parents, because of the religion and because of my learning problem didn't believe that I could have children. Maybe they thought I should not have children….

But I did have children. And it wasn't a bad thing.

Being a mom with a learning problem has also helped me to be a better mom to my kids. "I know that it takes them longer to understand things. I know that I have to be patient. Because I know what it is like to feel stupid, for other people to make you feel that way" (IT 3, pg. 6).

I know what it is like to have a disability. I know what it feels like. And I also know how they learn.

So I think there is a part of me that understands my children more than others and there is a part of me that feels bad that they have a disability. Sometimes I think it's my fault. And sometimes I don't think about it at all.

"I am very disappointed in a way, that what I had is passed on to my kids. That part is very disappointing to me that what I have is passed on to the kids. That I have a learning disability I thought that it would not affect my kids". I think my family looks down at me and the kids because of our handicaps. They look down on us because "having a disability in my culture is not good"(It 3, pg. 10).

That's why sometimes I do not want to see my family. I feel bad about myself and bad about my kids. I hate to look bad in other people's eyes. I want them to see that we are doing well. That as a family, we are getting there.

My life has had " … It's up's and downs, growing up I had my disasters. When I was younger I came close to drowning. But someone found me, under the raft. I would not have lived. But maybe its God's way of saying that she is not ready to go up. I am still here today" (IT2, pg. 2, line 8).

And I am still fighting.

I hope that people can see, that I am not angry; I am a fighter.

4.4 Pria's Story

My husband says that I am crazy. That I am crazy because I don't do things right in the house or with my son. He says that he doesn't want to have another child with me because I am crazy. That's makes me cry because I want more kids (IT 3, pg. 4).

I have one child named Devang who is 5 years old. He will be starting kindergarten in September 2011. He has a global developmental delay. Both of my parents were born in Trinidad and they are both Indian. I was born in Canada, but I think of myself as Indian and a Hindu. I have been married to my husband Joresh who is a Sikh from India for six years. He goes to India for a few months every year. When that happens, me and my son stay with my mom.

They say that if a woman has only one kid then she is not good. Like she is not really good in the culture. Women in my culture, they supposed to have many children (IT 1, pg. 2).

It's the woman who makes the meals for the child, bring him to school, let him play. The woman does all of that in my country (IT 1, pg. 2).

Being a mom is important to me. It's what women do in my culture. My son is very important to me and he makes me happy.

I look at my son and I am very happy. But when he was about 2 years old, they say he has a disability. My mom says that he is fine. That he is just a little slow. Like me. She tell me not to worry. That he will be ok (IT 1, pg.6)

And she was right, I think. Before he couldn't talk. He would always be upset. Or we wouldn't know what he wants or what to do with him. I think that the daycare works well for him. He play with other kids and he learns to better talk.

In my culture, they don't really believe in daycares. The child usually stays at home with the mom (IT 2, pg .4).

I like the daycare. But I didn't want him to go there before. My mom she told me that the daycare is no good for him. That if he goes there, they will take him away. That the DYP (department of youth protection) will take him away. She said to me that he don't need a daycare. That we can teach him (IT 2, pg. 4).

I didn't know what to do. I didn't want my son to be taken away but I wanted him to learn more and meet other kids…

Then the workers had a meeting. Me and my son have workers from the community center and workers from the Readaptation Center. They told us that they were worried about Devang and his learning. They said that if we don't send him to daycare and accept services that they were going to call DYP {Department of Youth Protection}. And they did call the DYP.

The DYP worker came to see me and she said that they were going to keep the file open. They said that they wanted to make sure that Devang has everything he needs because he has a disability. They said that he should get services to further his development. They said that it wouldn't 'cure' him, but that he could learn new things.

I was so worried that they were going to take my son away, so I listened.

I don't really like having the DYP and sometimes the other workers in my life. It's too many people coming by me! I wish that they could be out of our lives for good. I know that sometimes my son don't listen, but that don't make me a bad mom (IT 2 pg. 5).

I already have people in my life to tell me what to do and how I should do things.

Growing up

It was me and my sister when we were both young. My mom and my dad were not living together. I don't ever remember them living together. My mom met my step-dad when I was about 3 years old (IT 1, pg .1).

I was a bit slow too when I was young. I had difficulty. I think it was because of the school that I went to. I think it could have been that my step- dad, when I was 3, he hit me hard in the head. I don't remember that, but, but my mom she told me. And then I became a little slow (IT 1, pg .5).

When I was young, I didn't really know that I was slow. I just knew that me and my sister were different. She got to do more things than me. And I went to a special school.

But my sister was very different than me. She was the smart one. Even though she was younger than me. She was also the one who could stand up. She fought much more than me. I am quiet. Even more quiet when I was young… And bad things would happen to me.

My mom used to hit me when I didn't pass at school. She would say that I was slow. She would get mad at my sister but would not hit her.

I had a hard time at home. It was really hard for me when I was young.

My step-dad he would rape me. He would wait until my mom would go out and then he would stick it inside me. I told the teacher at school about it. And then they talked to me and my mom. My mom she didn't believe me at the start. She said that I was lying (IT 1, pg .2).

It happened for a few years. It still makes me upset today. What happened with my step-father. And because my mom she didn't stop it from happening.

It didn't happen to my sister. I think maybe because she wasn't like me. She wasn't slow like me. And she would speak up.

My step-father even showed my mother what he did to me. In front of me. He got on top of mother. With no clothes on. And I had to watch all of that (IT 1, pg.3).

Even sometimes I will start to cry when I think of all this. It is something that I cannot forget. Sometimes when I am on the bus, looking out the window, I think about this. And I cry. Why was all this happening to me? This is not a normal family!

I have two social workers that I sometimes speak to about this because it never goes away. They tell me that it's not my fault. That it was not because I did anything bad. Sometimes I believe them…

At school it was hard too. They tease me. They call me retard. They call me stupid Packi. I never had any friends (IT 2, pg. 5).

I was lonely sometimes. But when I was alone no one could hurt me. So sometimes it's good to be on your own. I was by my own a lot at school.

One good thing about that school is that I learned things like for jobs, I did stages to learn how to work. I did a stage in a store once, I liked that a lot.

A stage is like an internship where persons with intellectual disabilities are placed (by a socio-professional integration agent through a rehabilitation center) in a work environment such as a store or a company. A stage in itself is not paid, the participants receive just below 50$ every two weeks (above their social assistance check) and have their bus pass paid. A stage can be temporary, where persons transition to paid employment (that is usually subsidized by the government) or can be permanent, in that the person will remain within a stage. Very few persons with intellectual disabilities will transition to a paid job.

One day I want to have a paid job and bring money home for my husband and son. I don't always want to do a stage. I want a real job.

My husband

I was 19 years old when my mom arranged the marriage with my husband. He was already living here in Montreal. His cousin had arranged for him to come here. He just came here for a few months from India. I think they were hoping that he would find an Indian wife.

He was in his 30's at the time.

He knew a man that lived in my building. He came to see that man and then saw me then. He asked my mother if he could marry me. But it was pushed by mom. I didn't know what to do. I told her that I wanted to get to know him. Like 4 months. But it was pushed (IT 1, pg.3).

And as usual, my mom didn't listen. She wanted it her way.

He told my mom that he liked me. That he liked the way that I look. And I didn't really have a choice. That's why I am mad at my mom. She pushed me to do this. Maybe she wanted to get rid of me (IT 1, pg.3).

I sometimes felt like my mom she didn't love me. Like she was trying to push me away. It was a feeling that I always had.

I did want to get married. And have a lot of children. That was very important to me. But I think that I was too young. I could have stayed in high school until I was 21 (IT 1, pg.5).

But instead I got married at 19 years old. It was a very small ceremony at city hall in Montreal. We then had a big Indian meal with my family and a few friends of the family.

At the beginning my husband was ok. And then he became more controlling. Maybe it's in his country. Where they control a lot of things. That you have to control the woman. I don't like that. I don't think that's fair (IT 3, pg.3).

Like my uncle, he's from Trinidad and his respects his wife. He has to. If he was like my husband, I am not sure that she would stay with him. That even if divorce is bad, you shouldn't stay with a man who is mostly bad.

I was married a few months before I found out I was pregnant. I didn't even know. I was feeling sick. I even passed out once. And then I got a blood test at the hospital and they told me I was pregnant.

I was surprised but happy! My mother was not happy I was pregnant. I am not sure why. But she once pushed me when I was pregnant. I think she wanted to kill the baby inside of me (It 2, pg. 5).

I sometimes think that my mom she was jealous of me. Because she got divorced twice. And I am still married; I am still with my husband. And she's upset that I have someone and she doesn't. She will sometimes tell me that he is not a good husband and that I should leave him.

He doesn't do too much my husband. Me I take care of Devang. He doesn't help. He sleep. He watch TV. I don't want to force him. I don't want to make him angry with me (IT 2, pg. 9).

I get scared when he gets angry. He looks at me in a mad way. And he yells.

I can't have another kid. My husband thinks that I am crazy and that I can't take care of another child. He thinks that because the DYP is involved that it is my entire fault.

He also tells me that it is my fault that Devang is a little bit slow.

My husband blames me. Because my son has difficulty. He says that there is a lot of kids that don't have difficulty. That learn faster than him. That my son is slow because of me. I tell him that it is not my fault. That I didn't know everything (IT 3, pg. 5).

It's not my fault. He was born a little handicapped (IT 3, pg. 5).

But if it's my fault, then why doesn't he help me more with the kid? He just wants to blame me for all the things that go bad. He's like my mom! (IT 3, pg. 7).

I really want more children. It makes me really sad that I will not have that. That I can't give Devang a brother or sister.

So I told the worker that I want to work with babies. So that I can see them and play with them every day. I have a worker from the readaptation center who is going to help me get a job.

I *know that I am slow, but my husband I don't think he knows that…*

I don't think he understands. I think he thinks I am smart. Like one time I made a mistake. I ordered pizza for my son. I gave the guy 3$ for tip. Then my husband asked me for the money. I told him that I gave the guy the money for the tip. And he threw the box of pizza at my face and then he left. He threw everything in my face. I didn't eat. I just cried (IT 3, pg. 6).

I don't think he understands that I have trouble with counting and learning. I don't know why he stays with me. If he thinks I am crazy. Or he gets angry all the time.

He loses his temper with me, more than he does with his son. I would rather he yell at me than my son. My son is small and I have to protect him.

My husband also controls the money. He gets the money in our account and he decides what we buy or what we don't buy. I always have to ask him for money. Most of the time he says that we don't have any money left. I don't always believe him! I often wonder what does he spend our money on?

He goes to India for a few months a year. So he has money for that!

It's hard because sometimes I want to buy things for my son or go to Dairy queen for an ice cream. The social worker had to tell him to buy toys for Devang because he didn't want to.

Sometimes I think why did I marry this man…

My mother she pushed me to do this and then she want me to get away. They both want to control me. The take some of my money and they don't like each other. I think it's because they want to control me on their own.

Sometimes my mom and my husband, they tell me what to say. My mother tells me what to say at meetings that I have with the workers. I don't like when that happens because the workers get mad with me. Like when I didn't want to send my son to the daycare. I said I didn't want to because my mother she force me. I think that it wasn't a good idea (IT 3, pg. 6).

Sometimes I feel caught in the middle of my husband and mother. I don't always know who is right who is wrong. I don't want to have to choose a side. I don't like that because I don't want anybody to be mad with me (IT 3, pg. 6).

Me and my son

Being a mom is not so easy! But the good thing about being a mom is that my son is mine.

I do everything for my son. I wake him up, give him the breakfast and get him ready for school. I take the bus in the morning to bring him and then the lady at the daycare drives him back.

When he comes back home I prepare supper. Most of the time my husband is not there. He doesn't really work but most of the time he is out. With his friends or something.

My husband wanted to bring a lady from India to help me with Devang. He say that she can live with us and help me with Devang. I don't want that! I don't want another lady in my house, with my son! I don't think that's a good idea.

For me, the best part about being a mom as always having your child with you. Is that you are not alone. Even if no one else is there, you have your child (IT 4, pg. 5).

I think about my son's future. I want for him to learn. To be smart. And to have a good job. Me I went to Lasalle. I was slow. I had a lot of difficulties. I don't want him to be slow like me. I had a lot of difficulty with my family. And school. I want a different life for Devang. And to be happy (IT 3, pg. 5).

I know my son will be better than me in his life. That he will do something good. And I can say, that is my son!

4.5 Dung's Story

"How to make the spring rolls. Like my mom would teach me. You need the bean sprouts, minced meat, lettuce, shrimp, noodles and pork. You then dip the rice paper into the hot water and boil. Then you put all of the ingredients in the rice paper and roll. Serve it with Hoisin sauce or with peanut sauce" (IT 2, pg.3).

Making and sharing food is an important family tradition. When we get together as a family we always have spring rolls. All the women in my family know how to make spring rolls. My family is Chinese but I was born in Vietnam.

I am a wife and mother of three boys; Mark 21, Laurence 20 and Michael 15. My husband's name is Joe and we had an arranged marriage. We have been married for 25 years. He is from Vietnam. Me and my husband own our own house and I have a beauty salon in the basement. I cut and color hair.

This is our story.

Life in Vietnam

My mother and father were born in China. My parents told me there was a lot of poverty in China, in the villages that they were from.

"… There was no food in China for the whole village. They were catching the fish in the pond but the fish were very small. Not enough fish for the whole village. So that's why my grandmother and grandfather went to Vietnam with my mother. Not enough food to eat" (IT 2, pg. 1).

Both my mother and father's family moved from China to Vietnam when they were young. My mother's family knew my father's family even in China. When both my parents were about 20 years old, their families arranged their marriages. It made sense because they knew each other from when they were in China, so both of my grandparents knew that my father and mother came from good families.

My brothers and sisters and I were all born in Vietnam. We are ten brothers and sisters in total. I am in the middle.

I have happy memories of growing up in Vietnam. One of the things I remember most, was my parents home business.

"My parents they had a business at home. And my mom and dad have a maid to cook and clean the house and look after the children. My mom and dad had one boy and one girl maid. The boy helped my dad do groceries and the girl helped my mom with cooking and cleaning. Look after the kids. They stay in the same house with us" (IT 2, pg. 2).

The boy and girl maid were like a part of our family. The boy maid stayed with us for 15 years. We were lucky to have them with us because my parents were very busy with their business. The only bad thing was that some of the girls that would help us would also steal sometimes. I guess they did not have money for their family. To feed them. But my mom when she found out she would have to tell them to leave. And then we would have another girl help out.

I had a good upbringing, especially when I was young.

I liked going to school. I liked going with my sisters and my brothers. We would walk to and come home from school all together. Sometimes, after school, we would stop and go in the water before we went home. Especially when it was really hot. My brothers they liked to splash me. And I would splash them right back!

When I wasn't in school, I would help out in the kitchen.

"I would help my mom and maid cook at lunch time and then went back to school. I helped cook rice, meat, sometime I cook fish, help my mom wash vegetables. And watch her how to cook. In the evening after supper we just go out and play. We play tennis every evening" (IT 2, pg .3).

We had a big area around my house to play. And when we weren't helping with the store or cooking, we could play outside together. It was fun because we were such a big family, I had a lot of kids to play with.

There were always people coming to my house too. Coming by to buy groceries. We would also sell some spring rolls, dishes with noodles and spicy chicken. We all took turns helping my parents in the store. They would never ask me and my younger brothers and sisters to count the money.

I am not sure why. Maybe it's because they thought I wasn't smart enough. Maybe it's because I wasn't good at math. I did notice at the time, why they didn't ask me, but I didn't say anything.

We had a nice life. Until a communist government came…

"But then the communists came to Vietnam in 1975. And then things changed. We could no longer have maids. And they needed help for their store and for things at home" (IT 2, pg. 8).

"And they {my parents} didn't want me to go to school anymore. They don't teach Chinese. They only teach Vietnamese. And my family they don't let me study. Then I went to learn how to sew the clothes for one year. And then I stay home and take after the grocery store. And I also helped them cook too. And so no more maid, no lady or man to help in the house. So my parents won't let me go to school. I had to stay home and help them" (It 2, pg. 8).

I felt really bad about not going to school. Or only going to school until grade six. All my brothers and sisters went to school. Some of them even went to University.

I think that my parents think that I am dumb. That I am stupid. That's why they wanted me to stay with them. Why didn't they ask any of my other sisters? Why was I the only one to have to stay at home with them?

I wanted to go to school. I wanted to learn more things. And I wanted to be smart. Just like my brothers and sisters.

The way my family thought of me was the same way that the teachers at school thought of me.

"My teachers think that I am dumb too. They used to say that to me. But I wish that I could have gone more to school. So that I could be smart like my brothers and sisters" (It 2, pg.3).

We lived in Vietnam until I was 17 years old. Things were getting bad. And the government was getting stricter. So my parents wanted all of us to get out before it was too late.

Before we lost everything. It was really hard because during this time, when we used to go out in the village in Vietnam, my parents told us to keep quite. They didn't want to draw attention to us because we spoke Chinese. Because if we did then maybe they would do something. The people that worked for the government. The communists.

Leaving my home

"I left Vietnam by boat. In 1978. I remember in October. But I forgot what date. I was on a boat for 7 days and 7 nights. Then I end up in Malaysia on the land. But they won't let us come in because we have no food or water to drink" (IT 3, pg. 1).

The boat that we were on had a hole in it and water started to come in. People were screaming, because they thought we were all going to drown. Then we all had to jump out of the boat.

They found a place close by, on land. When we first tried to go in, they told us to get out. They came towards us and then hit the men, not the women or children. And we told them that our boat doesn't work well, that there is a hole and we had nowhere to go.

It was hard because we only spoke Chinese and these people were from Malaysia. So it was hard to communicate, especially at the beginning.

I came on the boat with my three cousins. I was the first one from my family.

These people sent us to a refugee camp in Malaysia. I had no idea what a refugee camp was and I had no idea how long we were going to be there.

I was there for two long years. I missed my family a lot. I would send them letters. And they would send letters back to me.

It was strange being at the refugee camp. There were so many people. And I used to live in a big house, with lots of land. We even had servants! And at the refugee camp if you didn't like the food then you would starve.

When you were hungry or thirsty you had to wait until it was time to eat, until they gave you food.

There was not a lot of people my age at the refugee camp. There were a lot of young children and adults. But not a lot of people who were 17 or 18 years old. So while I was at the camp, I stayed mostly with my cousins.

It was crowded and hot with all those people at the camp. You couldn't really breath very well.

And just when I thought that I couldn't take it anymore, I would receive a letter from my parents. They would tell me to be patient. That soon I would go somewhere much better. And that gave me hope.

About one year after me, the rest of my family would leave. They also left Vietnam by boat.

My parents told us before I left that we have to stay at the refugee camp. And wait for my older brother. Once he would go somewhere we would follow him. So that we would end up in the same country.

My brother he got accepted in Newfoundland. He moved there and then wrote us a letter. He told us that we were all going to live there until my parents came to Canada and we would all settle in one place together.

And then we got sponsored by the church people in Newfoundland. They were very nice people. Very friendly too. They got us an apartment and helped us look for jobs.

I was so happy to leave the refugee camp! It felt like we were going to be there forever.

In Newfoundland, we stayed 7 of us in an apartment, my older brother, sister and three cousins. It was a small place with two bedrooms. But it was so much better than the refugee camp. I shared a bed with my sister. At the refugee camp I had a small floor mat and a blanket. I was so happy to sleep in a bed and have a room!

When I got there, I did not speak a word of English. I went to school every day to learn English. I did homework every night. I watched TV. in English because I really wanted to learn.

And on the weekends I worked at a hospital in the kitchen. It was my first job in Canada.

We stayed in Newfoundland for one year and then we went to Alberta. My parents were already there.

Having an arranged marriage

A few months after we got to Alberta, my cousin told me she found a husband for me. It was a man her husband worked with. He was from Vietnam. She introduced me to my husband. I knew that he would be my husband and we got married after we saw each other three times. My cousin and her husband were with us every time that we met each other; to keep an eye on us.

“In my family, it’s very important that marriages are arranged. Because in Vietnam you don’t date. Your family find you a husband or a wife. Nobody dating before they get married. They have to be arrange married only. And that’s why the marriage lasts longer when they get married. It last longer because the family they know you better” (IT 3, pg.2).

“In Vietnam I don’t hear divorce. When I grew up I never hear any divorce. But when I came to Canada, I heard a lot of divorce. I hear 50% divorce. And wow, I was surprised, in this country it’s so easy to get divorce. I don’t believe it. And sometimes I look back at my parents and I really admire them” (IT 3, pg. 5).

“I admire my parents because they can live together until they die. But sometimes, I disagree with him, my husband. I don’t like what he does to me or something I don’t like it. But I still have to stay with him. I can’t divorce him because I have three children. Even if he does not treat me right I still have to stay with him. Because my culture, won’t let me divorce him. Because if I divorce him then I feel ashamed. I feel bad. I feel like I was a bad girl because the marriage don’t work” (IT 3, pg. 4).

Dung always knew that she would have an arranged marriage, as this was what was done in her family and culture. And when she got married, she knew that it would be for life, no matter what the circumstances. Dung expressed her discontent within her marriage, because of the way that her husband treated her; he ignored her for the most part or criticized her for the way that she disciplined or didn’t discipline the children and sometimes called her stupid. She also recounted how her husband never wanted to do anything in public with her and her boys. Leaving her husband wasn’t an option as she would be the ‘bad’ one and she knew too well what that felt like to be given that label within her family and culture.

My “sickness”

My family is close by as they live close to my house but I do not always feel close to them. Sometimes I like having a big family and sometimes I don’t. Sometimes I feel like I am part of my family and sometimes I feel alone. But most of the time I feel strange in my family. Like left out.

When I asked Dung, how her family felt about her, she looked down at the ground and said:

“But I think that my husband and family think that I am not disability. They think that I am stupid. They think that I am stupid. But that’s ok. They think that I am stupid. But that’s not ok” (IT 1, pg. 10).

Tears ran down Dung’s face as she recounted this part of her story. It was clearly not ok that her family thinks of her as ‘stupid’.

I sometimes think that my family is ashamed of me. Because of what I am. Because of what I cannot do. And sometimes they ask me, why are you like that? I don’t always know what they mean. Do they mean why am I me?

The way they think of me really makes me sad.

So sometimes I don’t want to talk to them. I stay quite sometimes when we are together as a family. If I say nothing then maybe they won’t pick on me. And I think they blame me for the problems with my kids. They think I am a bad mother.

“And my husband he never wants to go anywhere with me or my children. I don’t think that he cares about me. He doesn’t want to make me happy. It’s like he can do whatever he wants” (IT 3, pg. 9).

My husband thinks that I am sick. That people at that place are sick too. And he does not want to be around them or he does not want me to go. But I like going to those parties. I like being with those people. I don’t feel alone. And they don’t think they think I am stupid.

I am talking about Contact. It’s a place for people with disabilities and their families. They have gatherings and they give support. I think that they have helped me. They listen to me. And I feel that I am not the only one that has problems with my family. It sometimes feels like being a part of a family, when I go to these gatherings.

The people at Contact don't make me feel like my 'real' family. Or my culture.

"In my culture, people with the disability, they think they are sick. Or stupid. They don't say they have a disability. They just use bad words like sick, dumb stupid. And in my country they hide them. They hide them in the home so no one knows. Because that make the family look bad. Or sick" (IT 3, pg. 9).

From the outside, Dung and her family look very different from the other mothers and their families in this study. She has her own home in a nice neighborhood and has her own business in her basement. Despite the material things that Dung had, she was one of the moms that struck me as being the most in pain. She openly talked about the pain of being different in her family and culture. To the point that she sometimes thought of ending it all.

She also described her ambivalence towards her identity as a woman with a disability.

"I sometimes think that I have a disability but sometimes no. Yes that I, I cannot think what I should do, how to deal with my children. No I am not disability because I can cut hair, I can cook. And no I don't know how to discipline my children sometimes and sometimes I don't know how to deal with them" (IT 1, pg. 9).

I sometimes wish that my husband and family could see what I can do. And not just what I cannot do. I wish that they could say that I am doing good. That sometimes I am good.

But I know that's not how they feel.

"Sometimes when I think about all this I just ignore them. I live in my own world" (IT 2, pg.4).

Things that make me happy

The workers say that I have to find ways not to be sad all the time. They helped me make a book of pictures, of things that make me happy. They want me to look at these pictures when I am feeling bad or sad.

I feel sad a lot when I think about my situation. I feel bad inside a lot. Maybe I feel bad about the situation with my family. Because what is happening with my son and how I don't feel good in my family.

My sons will also hear what my husband says, when he calls me stupid and they will call me stupid. I know that children are not supposed to call their mother stupid. I know that they shouldn't say such things to their mother.

So I try and look at my book of pictures when I feel this way.

I have a picture of a laughing Buddha. We are Buddhists. We go to the temple sometimes, but we can pray at home. The laughing Buddha he brings us luck. Luck with money and the family. When I pray it helps clear my head; I don't think about all the bad stuff that sometimes takes over my head.

I took a picture of an angel. An angel that can watch over us. And guide us when things are hard.

I have a picture of roses in a garden. I love flowers and gardens. They are very beautiful. I love to watch things grow and become so beautiful. I have a nice garden in my backyard that I helped plant and water. They smell so nice. Sometimes I will just go in my backyard, with a cup of tea, and look at my garden.

My worker took a picture of me with my mannequin. The one I cut hair with. I just learned a new hair cut with layers. And also a different way to cut hair. It makes me proud that I can do that! I have regular customers that come to see me, I usually have haircuts every day.

I also take pictures with my family, there are a few in my picture book.

I took one where I am feeding my mother and my boys are all sitting beside me. Because a good mother and daughter she cooks and feeds her family.

When I look at this picture, I feel good and sad. Good because my mother is smiling and sad because I know that my mother is getting older and she won't always be there. She can sometimes be the hardest on me. But I know when it comes from her, she says things, because she wishes things could be better.

My mother wants me to have a good life.

There is another picture of my family.

“My husband wants us to send this picture to our family in Vietnam. This one where my husband, me and the kids are all sitting together. To show them that we are doing ok. Or we look like our family is ok” (IT 3, pg 9).

This picture, of the family, sitting together closely at the kitchen table, with about 10 different plates of Chinese food represents (to me) keeping up with appearances. They are all together, eating traditional food and looking straight at the camera. This picture tells a story, the story of what should be and Dung’s story tells a different tale (LP, Reflective journal, IT 1, May 29th 2010).

My boys

“My family is very important to me. In Chinese culture, family is number one. It is supposed to be the most important thing” (IT 3, pg. 10).

I have three older boys Mark 21, Laurence 20 and Michael 15. Having children is a very big responsibility. It has been very hard to have three boys. And I worry about them all the time.

I worry a lot about my youngest. He don’t listen to his parents. He listen more to his older brothers than his parents. I don’t know why but he does.

He steals from us. I had money in my purse and he took 70$. I told my husband that he stole from us and he talked to him. He said that he took 10$ and gave it back to us.

I am very worried about that. I am not sure what he does with the money. Maybe he goes to the movies and out to eat with his friends. But I worry that he might do stupid things with the money. Like buy drugs.

I feel very bad and worried. Because I talk to my husband and the workers about Michael but nothing changes. He also took my credit card once and played games on the computer.

I sometimes feel like nobody can help us with this problem. I don't tell my family because they will say that I am a bad mother and it is my fault. That I am the bad girl.

"My older boys are doing well and I am proud for that. My oldest works with old people as a nursing assistant. He is studying to be a real nurse. My other son is working in a store. I hope that they will make a lot of money so that they can take care of us!" (IT 2, pg. 9).

When people come to my house they will see how family is important to me. I have lots of pictures in my living room wall of my family. I have pictures of the boys at their graduation. I have family pictures of the 5 of us. I have black and white pictures of when we lived in Vietnam. I have pictures of my husband and I when we got married. One of each of the kids on the first day of school.

I like showing people these pictures because we look like a happy family.

In my photo album, I have pictures of my family gatherings. We get together for Christmas, Chinese New Year, birthdays… And we always have a lot of food. I take pictures of the food because we also have food when my family gets together. We have chicken noodles, spring rolls, Chinese rice, chicken balls, spare ribs…

Making food is something that I am good at. I watched my mother in the kitchen. And even though it took me a little while to learn how to cook right, it is something that I can do. Maybe my older sister is a better cook than me, but that's ok. My boys eat well and that's what matters.

"If I had daughter's I would be teaching them how to make this food. So that they can teach their daughters" (IT 3, pg. 10).

4.6 Mary's Story

People ask me why I have this tattoo. It's for my girls. My girls that were taken away. The heart is how much I love them with their names. The feather is a part of our native tradition. It is there because even though I will not see them maybe even ever again, I can look at it and it reminds me of them and how much I love them… (IT1, pg.3).

My name is Mary. I have three children; Elizabeth 10 years old, Lisa 8 years old and Matthew 6 years old. Elizabeth and Lisa were adopted eight years ago. It was a closed adoption, which means I can't contact them and they are too young to contact me. Matthew lives with me and my boyfriend Charles. We live with a supportive roommate, Jessica, but we have the basement of her house, in Calgary, Alberta. I am a Métis; Cree, French and English.

My Childhood

I didn't have a very good childhood. I blocked some of it out. My parents were more into partying than taking care of us. They would go out for most of the day and night and drink and do drugs. That left me to take care of my two younger brothers. I would make them breakfast, lunch and dinner. Make sure that they would go to school. And make sure that they would be clean and go to bed at a good time. I was about 8 years old when I started doing all of that (IT 2, pg. 4).

I also had an older sister, but she was not around much. She is two years older than me but I could not count on her as an older sister. She was doing her own thing. She started going out and partying when she was young.

We never really got along. Never. When she was around we used to fight and I remember we also took turns locking each other in rooms.

I didn't understand why my sister got to go out and have a good time and I was stuck at home taking care of my brothers.

It didn't help that we moved a lot when I was younger. I was born in Saskatchewan. Then we moved to Calgary when I was about 8. Then to BC for a few years and then back to Saskatchewan where I spent most of my teenage years. And then we went back to Calgary.

I liked being in Saskatchewan the most. I spent most of my teenage years there. We used to go up to the valley and go berry picking. My grandma, my mom's mom used to bring me there sometimes, just me and her. We sometimes wouldn't talk at all when it was just the two of us. But I liked that. It was quiet and not at all the way it was when I was at home.

My grandpa died while I was there, in Saskatchewan. I was really close to him too. I was so upset when he died. I stayed in my room most of the time. Smoked right outside my bedroom. I would go to school and then back home. But would hardly speak to anyone. He was buried on the army base in Saskatchewan. I miss them both to this day (IT 1, pg .5).

I didn't have a real childhood when I was growing up. I went to school, but I was the shy type. I would keep to myself most of the time. Not like my sister who was the popular one. No one really knew me at school. I would not really talk to anybody. And I would not tell them what was going on at home.

I felt different than everyone else at school. I think because I was in a special ed class and because of everything that was happening at home. I didn't think anyone would understand. They would also call me names, like savage, because they knew that I was native (IT 2, pg. 7).

When I was about 16, I started to party too. I think that I had enough of doing stuff around the house, of being responsible, when everyone, including my parents, were going out and having a good time.

I started hanging out with the party crowd. My sister she introduced me to them. We would sit around, drink and mess around. I finally felt that I was accepted by people my own age. They didn't care who I was and where I came from.

I became pregnant with Elizabeth when I was in high school. I tried to be home schooled at the time but it was too difficult. It was hard for me to watch my math videos, take care of Elizabeth and then make sure the boys were ok (IT 3, pg. 3).

When I was growing up I couldn't really count on my parents. My mother's brother was like a father to me. My uncle was a really important person in my life. Whenever I would need something he would be there. When I didn't want to listen to my parents fighting, I could stay with him. I actually got my tattoo with my uncle. I wanted him to be there with me and see the tattoo first. The one with the girls' names and the feather. When I was younger, he was the one who didn't party as much.

Even with everything that has happened in my life, it's remained with me, that family is really important to hold on to. They can show you traditions and they know all about where you come from.

I don't like talking about growing up to many people or very often. There are things that I would like to forget. But family is important. Culture is important. Even if sometimes it's not always good to be around them (It 2, pg. 5).

It's important for me that Matthew knows his family and culture.

My parents weren't always the best growing up but…You can forgive the person but you'll never forget what he's done or what they have done. But you can't hold a grudge forever. I held a grudge against my dad for a long time until recently. You could, but where does that leave your kids? That's not fair to them not see part of their blood because of something that happened before they were born or when they were younger (IT 3, pg. 4).

Even though sometimes they act stupid, or I don't think he should be around some of the bad things, it's still his dad, it's still his granddad, it's still his blood. His family (IT 3, pg. 5).

My dad he once came to visit us in Calgary. I was about 18 years old. And he left without saying goodbye. I was really upset and didn't understand what was happening. I stopped talking to him for a few years.

But I wanted him to know Matthew so I started talking to him again a few months ago.

Because blood is thicker than anything. You need to know where you come from. Especially from my culture. We got to stick together (IT 2, pg. 2).

I was struck by what I felt was a paradox; Mary described the abuse and neglect that she had endured from her family but she felt compelled to maintain these connections in the name of traditions and culture. When I asked her why she felt people in her culture had to 'stick together' she responded by saying because "we are all the same" (IT 2, pg.5).

My Culture

There are lots of native traditions that I do every day at home or that we have in the house…

I have a dream catcher above my bed. Dream catchers they basically let the good dreams come true and they catch the bad dreams on the spider webs. And you hang them above your bed.

I have sweet grass and sage. We used to smudge together. Smudging is basically cleansing your body. You put it in a shell and you never light either one with a lighter, you have to light it with a wooden match. And then when you are done burning it you put tobacco for an offering and you burry it in the ground in the four directions. Because in the native tradition, when our family members or someone close to us dies we cut our hair and then we bury it. To remember the person that passed away (IT 2, pg. 10).

I have all sorts of native things that are in my house. I have a wolf blanket in my bedroom. I make native bracelets and necklaces. I go to pow wow's and drum dances. I even like to listen to native drumming music, especially if I am upset. My grandma and grandpa told me that all these things are important for us native. It's important that we keep doing it so that our kids can do the same thing. It's traditions. And I feel good when I am doing it or around it (IT 1, pg .11).

Wherever I live, whoever I live with, I always have my native things with me. It is a part of me. I am proud of that today. I became proud of that. Even though when I used to be a kid, I used to hide that part of me because they would make fun of me. They used to say things because I was native and because I had learning problems, because I was in a special ed class.

In my culture, it doesn't really matter if you have a disability. Some people have severe disabilities and others they might just need a little help doing things that all people do. But you can't judge (IT 2, pg .5).

Mary's perception of her culture's interpretation of disability was the most positive of all the women in this study. Her interpretation goes along with the collectivist ideas of disability where accommodation of a disability happens naturally within a culture where its members instinctively take care of each other.

My Girls

I know what it feels like to be judged, and it got worse when I had my own kids.

I never really thought of having kids. No one really talked to me about having kids or not having kids. It's just something that happened. Every time it was a surprise. I never planned to have any of them (IT 2, pg. 8).

Don't get me wrong though, once I had each of my kids, I wanted them; I wanted to keep them with me. I had them because I wanted them.

I met the girl's father through my older sister. She had gone out with him. My mom also slept with him too. We were never really serious. We would get together but we were never really together.

I was living at home when Elizabeth was born. Like I said, I was still in high school. I was so young that I didn't always know what I was doing. But my mom for the first time in my life would help me with her. The father was not around, every day anyways.

I became pregnant with Lisa about a year and a half after Elizabeth. I was still living at home with my mother and brothers at that time. I wanted to try and live by myself with the girls so I moved out and got an apartment. I remember it being really hard with two girls and hardly ever having anyone to help. It was really hard when they both would cry at the same time!

I remember that at times, I didn't know what to do. Or who to call. And I was also really tired!

And this was when child welfare got involved in our lives …

I think it was a neighbor that called child welfare. They couldn't tell me who it was because it's confidential (IT 2, pg .4).

After the child welfare file was opened, they watched me with the kids. They told me that I needed help with the girls and that I couldn't do it on my own. They told me that I needed to learn to be a better mom.

I was sent to this place called Pikaway house for parents to stay with their children. But that didn't work out, every time I didn't like join in crafts, they threatened to have child welfare come and take them. And it was the house parent, Louise who told me that (IT 2, pg. 2).

At Pickaway house they would try and help me with the kids and make sure that I was going to my appointments with the kids. But sometimes I felt like they were spying on me and telling child welfare. Twisting my words and making things look worse than it did. Child welfare was saying that I would take the girls at all hours of the night to see their father. Like even when it was below 40 degrees weather. I would keep in touch with him by using my cell phone but I wouldn't visit him like they said I would (IT 2, pg. 3).

They also said that I shouldn't see the girl's father with them. They told me that he was not allowed to be around children. That he was on probation (IT 3, pg. 2).

My mom I also think that she had something to do with all of this. Because when she was around, all "h" would break loose. She would be drinking and cause trouble with me or she would call child welfare and say this and that (IT 1, pg. 6).

I also think that my mother was jealous. Jealous of the fact that I had my girls and that they loved me.

Youth protection did not think that things were going well. They thought that I wasn't following Pickway house's rules and that my girls were not a priority in my life. I told them that it was not that way, but there wasn't much I could say or do; they had already made their decision.

Youth protection put them in foster homes when Elizabeth was about 2 and Lisa was just a baby, about 6 months old. I would have two hour supervised visits with them at the child welfare office. They would cry every time they would have to leave.

I hated going over there for visits. First we were never alone and we were always watched. There was always a social worker with us. Second, I knew that every time we would have a visit, it would be so hard on all of us to say goodbye.

It was a few months after that that we had what child welfare calls a ‘termination visit’. This is where a mother or father has to say goodbye to their children when they are going to be adopted.

I remember it like yesterday. I see that day in my head; it’s something that never leaves me.

As soon as I found out about this, that they were going to place them away from me for good, I started writing them letters, put together photo albums for them so that they would always remember their family.

Matthew he was too young so I couldn’t take him. The driver he let us together for about a half and hour and then he rushed us out. Said that he had another visit across town. He was really rude. I don’t know if he got fired but I complained (IT 3, pg. 2).

I remember the last few moments together. I gave them each a prayer angel. And then I held them each in my arms and gave them a big hug. I told them that I loved them.

I held my tears back. Especially when I heard Elizabeth yelling “mommy, no”.

That was really hard. Really, really hard (IT 3, pg. 2).

I only found out a few months after that they were going to be adopted. And that it was going to be a closed adoption. I never understood why… I mean what could have been so bad that I might never see my girls again?

My son

What really helped me through the really hard times was Matthew. Having him there to take care of and him needing me was the best distraction after losing my girls.

He is 6 years old right now and is he ever a handful! He is really active and keeps us all busy.

I lost him too for 353 days when I was with my ex. He’s not the biological father of any of the children but Matthew thinks of him as dad. I met my ex through my sister. His parents had a farm a few hours from here. No one was living there so we moved up there. Matthew was about 2 years old.

I was very isolated over there. I can't drive so I would always have to rely on him to bring me to town. To do the groceries and stuff. No family and friends. He wouldn't let me speak to my family or friends, so I was really alone.

And one day, he hit Matthew until he was black and blue from his back down until passed his knees. Child welfare got involved again (IT 2, pg .4).

That's why I ended up moving back to Calgary from the farm to get Matthew home. They said that if I got rid of him and moved in with a supportive roommate that I could get Matthew back.

I didn't want to lose him like I did the girls so I did exactly what child welfare wanted. I moved back in town and got a supportive roommate. I lived with Gina and then with her daughter Meghan and about a year ago I moved back with Gina.

I was really scared that I would lose Matthew, too. But I was determined not to. I needed to protect my son. And I did.

I would tell any mom, take all the help you can get! Having a child doesn't come with any pamphlets (IT 3, pg .6).

And children they can take a lot of your energy, especially if you are sick. I have diabetes. I keep track of my sugars and try and eat right, but sometimes it makes me more tired.

Life today with Matthew is really busy. But what helps is that we have a good routine.

I get up then get Matthew up. Get Matthew ready for school. Then it's breakfast. I make sure he has everything for school. Give him his medication. Then he is off for school. And then sometimes I have a worker from 9:00-12:00. If it's nice outside then we will go for a walk. We could get groceries or she could help me with understanding the papers. And then we make lunch and one of us will go and get Matthew from school. He comes home for lunch and we eat together. And then we bring him back just after 12:30. And then I watch soaps until 2:00.Charles leaves for work around that time. And then around 3:15 I go get Matthew from school. He comes back and then he does homework if he has any. Then he'll have snack and go play outside for a little bit. Then around 5:30 we will have supper together and watch a little TV. Then its bath time around 7:30. 8:30 is snack, 8:45 brushing teeth and then bed 9:00 (IT 3, pg .6).

I have some help for Matthew and for me. Help can be good. I just don't like when people tell my business. Like when Gina would tell the doctors that I have Fetal Alcohol Syndrome or that I have learning disabilities. I didn't understand what her point was. Why did she have to tell the doctor's that? I wasn't there for me, I was there for Matthew.

I don't want anybody to think that because of what I have, that I am a bad mother. That they will take my son away because of that (IT 3, pg. 6). I think about losing him, which scares me to death!

Matthew sometimes doesn't listen or can get angry. It was really hard on him when he was away from us so I think he sometimes wants to test us! They say that he has ADD.

Over the years I have found some tricks to help out with him. When I give him his medication, I usually give it to him in the bathroom, with ice tea so that he can wash it down! If he's in the bathroom it's also hard for him to run away!

He also loves spending time with Charles. Charles is my boyfriend, actually fiancé. We had an elder perform a traditional native ceremony where he blessed our rings. We might not have been married in a church or have papers to show we are married, but we had a traditional ceremony which is important to me! We have been together a few years now.

Charles is really good to me and my son. He treats him like his own and he doesn't hurt Matthew like my ex did. Matthew really likes him and he loves when we all go fishing. So we tell him if he has a good week and listens then we can go fishing together.

I also do a lot of things with Matthew's school. Sometimes I volunteer and help the teachers. I also met with the principal when it was time for him to start a new school. We then had a meeting and Matthew was able to meet his teachers and get a tour of his school.

I still talk to Matthew about his sisters. Sometimes we will look at the picture album that I made with the girls in it. And Matthew knows that one day they will come home. They will come looking for us (IT 3, pg .4).

This picture above my bed is the last picture, of me and the girls with my son Matthew and my mom. I had bought them these new dresses and put their hair in pony tails. I like this picture, because we are all smiling.

I look at the picture and wait. Wait until they come home. Wait until I can hang another picture on the wall but this time all of my children will be in the picture.

4.7 Sheira's Story

And my daughter, she wants to change her last name. She says that kids make fun of her, that it sounds weird. But I have had so much taken away, and it's a part of me. That I just won't let that happen. And like I told her, the world has given you certain things and you have to learn to live with it. That's one of the things that I have had to learn the most is that you have to live with certain things in your life. And I am trying to change the things that I can actually change. Like what's really important to me is that me and Vic we always have this bond (IT 1, pg. 5).

The bond that I am talking about is with my daughter Victoria, she is 11 years old. My name is Sheira. I am 34 year old. I am single mother. I was raised with a white foster family but I am Native, Cree. I have one blood sister Violet and two adoptive brothers. When I was 15 years old I was placed in another foster home, Jenny's home, for people with disabilities. I was born with FAS and have some learning difficulties. Victoria has been living with Jenny since she was a few years old. I see my daughter one weekend every month and we celebrate all holidays together.

I want to share my story, our story.

For me it's really important that people are listening, that they can relate. That they can hear what it's like. Like its kinda like I am giving them a gift, for them to understand what it's like for people like me. I don't want the whole world to look at people like me and hate me (IT 2, pg. 7).

What it's like for people like me

I have FAS and learning disabilities. I was born that way. And because of that, people have made assumptions about me. They think they know who I am and what I can and can't do because I have these labels. But I don't want to be seen like that…

I just want the world to see me as a good person and not an alcoholic. Like at the hospital, when I gave birth to Victoria, there was a lady in there, I think she was on drugs, on crack. She was going through detox. She was going through labor and they let her take her baby home. And I am like, but I have something that I was born with and you won't let me take my baby home (IT 2, pg. 6)!

That was really confusing for me! The day that I had given birth to my daughter was supposed to be the happiest day of my life, instead it felt like I was put on the stand in court. Like I committed a crime or something.

At the hospital, I was giving them reasons to give me a chance! It was like it was an interrogation and I had to prove to them why I should be a mom. But the whole time I was thinking, that lady who was on crack you just gave the baby and that was it! And it really confused me. I hadn't done anything to my baby! I didn't go in there slurring or high. You know I'm sitting there working it and pushing my baby out. And she made some horrible choices and she got to take her baby home. And what message does that send to me (IT 2, pg. 7)?

I felt different from a very early age. I went to a special school and no one else did. Even my blood sister. She has FAE (Fetal Alcohol Effects), but she was in a regular classroom and she did everything to look normal! But I couldn't pull that off! I had to go to a special school with the 'special' kids.

I was jealous of my sister, I won't lie. Why did she get to be with all the other kids and I got separated? I would think why was I the one that was always separated? You know, school was not a good experience for me. It taught me how to read and write but other than that it was a horrible experience.

I got treated quite differently. I was always in a special ed class and that was not cool at all. That was horrible. For people with learning disabilities. But unfortunately I remember that if I made a mistake, she had a metal yardstick and she used to hit me on my knuckles if I had a wrong answer or in a corner. It was humiliating. I remember this one time because I didn't do my homework or something and I was in quite late, I think it was sick or something. And the teacher just looked at me and put me in the corner. And you know I tried really hard in school and trying for me is really difficult because sometimes I feel the more I try, the more I fall (IT 2, pg. 2).

I have grown up with people thinking certain things about me. Sometimes even before they met me or got to know me.

People have misconceptions about people who have FAS. It's like, is she going to cough on me, will I catch it or something. And it's like people don't want to talk about FAS, it's one of those things that people hide and I don't blame them, who wants to admit that they were drinking when maybe they should not of. But, then people like me come out and people don't want to talk about that either (IT 2, pg. 5).

And I think it's kind of a taboo thing because somebody has done this to you and no one wants to talk about that. That they have done this to another human being. But I have to live with this shame. I have to live with the fact that the world looks at me differently.

I feel different. You are definitely lower than the average person… I think there is a totem pole, for people. People with FAS, they are all at the bottom. And people that are crack addicts and go to jail, I feel like they get more respect and help than people like me (IT 4, pg. 6).

I was born like this. I was born with FAS. And as a result I also have learning disabilities. It's also hard for me to know what's right and what's wrong when making decisions. It's also hard for me because I am gullible; I think everybody always tells the truth.

My FAS has caused me some challenges in my life. And I wanted to meet the woman who did this to me and put me into this world. I also wanted to know what she looked like; did I look like her?

I tried contacting my biological parents because I really wanted to ask my mom why would she would drink when she is pregnant. I just wanted to meet the face behind the FAS, I really wanted to, but it just really didn't work out. She didn't want anything to do with me. Like I could understand… (IT 2, pg. 4)

A Disturbed Place

My upbringing is a little weird, it's a little bizarre. I was adopted by this white family. They wanted a boy and a girl, but instead they got two girls. And we are native so we are little savages and we came from very disturbed place. Like our real family was really disturbed. Made the Manson family look like peaches (IT 1 pg. 8).

My real sister Violet and I were adopted when we were about 3 and 4 years old. But because of the severity of the abuse we were not potty trained and we didn't really know any English. I am not even sure if I spoke any English (IT 1, pg. 8).

I have some memories of growing up with my biological family and they were not good. I remember my birth dad putting me in an oven. I was also told this story and I didn't think that I could have any children. I was told that my birth dad stuck a bottle; I think it was a beer bottle up me. And then it broke.

And my adoptive parents, I think they wanted a boy and a girl. So my dad took me under his wing and he raised me as a boy. I wasn't allowed to be a girl; I was not allowed to play with my girlfriends. I was only allowed to play with my brothers in the neighborhood. I wasn't allowed to do girly things like playing with chalk, or dancing that was girl's stuff! And so I was allowed to do sports, like BMX, skate board, baseball, t-ball. My dad used to say, "it will toughing you up, it will make you a good man" And I was always dressed in blue. My hair was always, I had a bowl cut, my hair was always short, and my sister was always long (IT 1, pg. 9).

The kids in the neighborhood used to call me a boy. They would ask me 'are you a boy or are you a girl'? I didn't really bother me because I liked being a tom boy. I liked hanging with the guys. And I really wasn't into those 'girly' things like jump rope or spin the bottle.

And then I was nine, my dad had a really bad accident. He was alone in the car. He became really different. Pretty messed up. In his head anyway. And after his accident, it was kind of funny how I was not his dude anymore, I was all of a sudden his little girl.

Sheira disclosed that she was sexually abused by her adoptive father. It went on for about five years before she talked about what happened.

When I said what my dad was doing she (my adoptive mother) turned around and said that I was lying and that it never happened. I was the one that came on to my own father. And the police believed them because of the FAS (IT 1 pg. 9).

And he was messing around with me until I was 14-15. And I couldn't take it anymore. I wanted it to stop. And I knew that it was not normal. I was starting to throw fits; I was throwing things in my room, punching the walls. And my parents were having a real hard time with me.

I think I was crying out for help.

My parents felt that they could no longer deal with me and my behaviors. I was brought to a home where there were other people that had severe disabilities. More severe than me. There were some that were in wheelchairs, some that couldn't talk. And that's where I met Jenny, she was the one that ran that house. I was ok with leaving home for the most part, I knew I would miss my parents, in a strange way. But I wanted the abuse to end.

I am so thankful that I ended up meeting Jenny and all the staff at that home. They were really the only positive people in my life. They really understood that I was lost and that I needed help. Because I could have ended up really bad, like a hooker or something around that road. And I recognize that and I didn't want to go down that road and my parents they had always put that in me. Like they always said that you are going to grow up to be a nothing (IT 4, pg.2).

They would also say things to me like: "You are going to grow up to be a criminal, jail everything (IT 4, pg.2).

Hearing these things from your parents is really hard. You sometimes start to believe them!

And they would also say that I couldn't learn very much.

"Why should we teach you anything it's just not going to sink" (IT 4, pg.2).

So, I really tried to push myself to stay away from all of that. And Jenny and the staff they helped me (IT 4, pg. 2).

They helped me see that I have strengths and that I wasn't going to end up like my parents told me I would.

Now that I am a mother, I look back and think how I might react if my daughter had gone through what I had gone through.

If my daughter had to go through that I would be really upset. And you know it makes me think, my mother had instincts, then why didn't she use them with me? Like I would do anything for my kid I would believe my kid no matter what, but why couldn't my mother do that for me? My mother sometimes she will not give me an answer, which is fine because right now she would rather pretend like it never happened. She rather like just try and have a relationship with me. But I can't have a relationship with someone who will not acknowledge what had happened (IT 2, pg. 4).

My parents ended up getting a divorce when I was 16 years old. They never really told me why…

You know my sister sorta blames me for the divorce, because she feels I had caused all this trouble. I might of caused a little bit of trouble but it was because of my behaviors, I was just trying to get somebody's attention. I understand that now that I was doing that because I was not a psycho-path but because there was a reason behind all of it. And you know it took me a long time to come and forgive myself. To say this wasn't your fault, that you are a good person and you deserve so much more then that (IT 4, pg.3).

A lot of the people in my family blamed me. It really hurt me that my mother didn't believe me. That she didn't protect me from this abuse.

Abuse changes you. It changes your family. Things were never the same between all of us after it happened; when I said what had happened. I don't see my family that much these days; my parents and my sister. I don't actually like seeing them; it brings me back to everything that happened. All of it. And how I was blamed for all of it.

And it gives me flashbacks and it makes me feel guilty. And I say to myself, is all of this really healthy? Do I need to be around these people that make me feel like this? Or what can I do to feel differently (IT 2, pg. 4)?

I am still searching for the answers.

Me and my princess

I didn't have a lot of luck with the men in my life. I have only had a few boyfriends. Ron was the most serious boyfriend I had. I met him at a party when I was in my early twenties. I got pregnant with my daughter after one month of being with him.

Ron was a drinker. Even slapped me across the face when I was pregnant with Victoria because I called him a liar. I told him to leave when that happened. And he did. I never saw him again. He never saw his daughter. And I never went looking for him.

I was 23 years old when I had Victoria. I was living alone in a public housing apartment at the time.

That seems so long ago…

I can't believe that my little princess is 11 years old now. She's in junior high. We have a very good relationship right now, but that's not how it has always been…

Since she has been born I have had to fight for her. And I didn't know that I wanted Victoria until I had her. I also knew it was my responsibility and I was obligated to show them {child welfare} that I can. I had to show them from the beginning that I could be a mom even though I had FAS (IT 3, pg. 9).

I guess they didn't really believe I could do it alone because they said that I had to move in with a supportive roommate, who was also a mom.

They said that I am unable, but I was living on my own since I was 18 at the time and I never had any issues with my rent or food. And I had no issues trying to provide for Victoria and I thought I was doing ok and then they stuck me in with this family (IT 2, pg. 4).

That is not what I wanted. It was not what I had in my mind when I had my daughter. I didn't want to live with another family and rely on them for support.

And the thing was, she was supposed to be helping me, she was supposed to be teaching me parenting skills. But every time Victoria would cry or do something, she would come downstairs and just take over. I didn't even feel like her mom.

So after a few years, I wanted to try to live in on my own and the workers said that they thought I was more ready. Victoria was about 2 years old at the time.

So I got an apartment, this apartment that I am living in right now. And things were ok for the first little bit, but I think it was really hard for Victoria to be away from everybody. That lady that we lived with, she also had kids, around the same age as Vic. And it was the first time that the two of us were alone.

But things were just getting worse. Victoria was always really angry and she was having these fits.

It was not a 20-minute thing, it was more like an eight hour thing. I would have to put her in a chock hold. Put my legs up around her and she would not stop, it was, if I let go of her it was I was getting things done to me. But I didn't like that because I didn't want to hurt her, I was always really careful that I was not putting bruises on her or she didn't have any red marks on her, or I would have to stop (IT 4, pg .7).

And if I put her in her room she knocked the door down or put a whole in the wall.

At this point I was really scared. She was un-predictable. And I didn't know what to do.

And there was this one night, where I called the workers and I was just screaming. I was hysterical. The workers told me that I had a psychotic break. That I was just pacing in the apartment and I was incoherent.

That night they called Jenny and she came to get her. I don't remember all the details; it is a bit of a blur. I had come to my breaking point.

Since that night, Victoria has been living with Jenny and her family. I think that this decision, of having her live with Jenny, was probably the best decision for the two of us.

And I just wanted to give my kid a better life than me. And I wanted to give her a chance that I never got. And to me it's the biggest gift that I can give to anybody (IT 2, pg.6).

A different family

My relationship with Vic is very different today. It has grown. She has grown. And she is struggling to understand her mother and our family. She is trying to understand what is the same and what is different in comparison to other families.

And I try and make her understand that her mother can't do everything. And there are some things that are really difficult for her. Like her family has to look different. Like I have to have people around me, like workers in order for me to do the things that I do. And I probably will have to have that for the rest of my life. I would definitely get into trouble. If I didn't have any kind of good advice, I would be screwed (IT 2, pg .6).

Victoria realizes that her mom is quite different because simple little things like remembering school meetings or concerts if I don't have somebody to remind me of those things then it will never click. But if I don't have it written on my calendar than I could miss it. And I have missed a few of Vic's events because I hadn't written down and that really put a crimp in me and Victoria's relationship. But I also had to make Victoria realize that it wasn't always my fault I just didn't remember and I would have been there if I did (IT 2, pg. 5).

And sometimes Victoria will ask me why don't you get a job like all the other moms? And I'm like but I am not like all the other moms. I said your moms got FAS, my brain is not like your brain. But you have a wonderful brain and your brain can do things that you only know. But mom's brain there are pieces that are missing and these are pieces that are never going to come back (IT 4, pg. 8).

When Victoria is thinking and asking questions about her mom, it makes me think too. Sometimes I am not sure what to answer, I just want her to know that none of this is her fault. And being different, does not mean bad.

And sometimes Victoria will get really frustrated because she really wanted me to help her with her homework right now. She is going to grade 5 and she wants to do her math or any kind of homework but it's like Martian to me (IT 4, pg. 9).

Sometimes it makes me feel so inadequate. Like it makes me feel I don't want to use that word, but stupid. And Victoria will say but it's so easy. And I see Victoria, she catches on really quickly, it makes me happy but it also makes me sad because she got her brains from her mother (IT 4, pg.9).

I see Victoria for a weekend a month. We usually talk on the phone every second day. But she's a busy girl. Jenny's got her doing brownies, or guides and she has swimming.

At the beginning it was weird. I wasn't sure about our relationship or how I could still be her mother from a far.

And I did realize that my job wasn't over, I can do a mothering job, not in the same house, but in a different way. So far it's working. We even say that we like each other. Even that we love each other. I am just grateful that my daughter and I will be ok (IT 2, pg11).

I also didn't know how Victoria would react to my decision, of having her live with Jenny.

When she is an adult we could always be friends. I just don't want Victoria to hate me because I've done what I have done. She knows that she is not here because I put her in a place so that she would get the things she needs so that she can be her own little person. I am really lucky to have met the people that I have had in my life, some of it was good and some of it was bad. I really wanted to stop that cycle (IT 2, pg. 11).

There was this one time in the counseling office where she(Victoria) said to me I know why we can't live together and she said she understands that we don't live together because of my tantrums and because of your disability and I understand that you still love me. And I love you because you didn't just abandon me, you placed me with people that love me and want to be with me.

And it's hard for me to see that other people are doing that because I should be doing that but I can't. And that's hard for me to say that to my kid, as much as I want to do this for you, I can't (IT 3, pg. 3).

That is probably the most difficult thing. To tell your daughter, that you can't take care of her and then have to watch as someone else does part of your job. But then again, I see how well she is doing which shows me that I made the right decision.

A missing part of me

I wasn't raised or allowed to know anything about my Native culture when I was a kid. Even at school when it was native day or anything like that my parents would write a note saying that I couldn't participate because it was against our religious views. The same as the sex ed. That was not permitted either. I was one of the only kids that had to stay out of the class.

But that's probably why I wanted to go to PICKS, it was probably the most rebellious thing I could do! I wanted to hurt my mom at the time and the only way I knew how was to learn about who I was and my culture. And I remember she threw a big fit about it. Because in her view, natives are evil and big drunks (IT 2, pg. 10).

Picks was a school where teenagers would go to learn more about their culture. They would talk about history. About traditions. They talked about stories that were passed down from generation to generation.

I felt pride when I started learning about my culture. It's a really beautiful. And I felt whole.

And I want Victoria to feel that pride. And when she was little I even put her in a native daycare because I wanted her to know who she was and where she came from. Just to give her a bit of her cultural heritage (IT 2, pg .10).

I do feel differently now that I have connected with my culture. I don't feel shamed, I feel more pride. And my mom would say, well you're white and I would say no, I am native. I might not be fully native, I guess my dad was white, he had red hair but my mom was full blooded. And I think if my parents had not made the issue that I was a little savage that I was a little squaw then maybe I wouldn't have gone and wanted to find out more about who I am (IT 2 pg. 11).

Things that help me get through…

I have had a hard life but that doesn't mean I have to be down in the dumps all the time. Besides my daughter and my culture, there are other things that I am thankful for and help me through the tough times…

My Support

The girls at Contact {a community organization for parents with intellectual disabilities and families with disabilities} they treat me with respect, like I am a human being. They don't see my FAS, they see me as a mom which is really important to me. And you can talk to them, and they probably think I am a good mom. And I wish I could do it, but between her fits and my FAS I couldn't do it. Like lots of things can get in my way and I have to figure out how to get around them or push them out of my way. The staff they are like my family. And they have treated me better than my own family (IT 3, pg .4)!

One of the workers at Contact tells me that seeing me is her favorite part of the day because I always make her laugh!

My sense of humor

You can't cry all the time, you have to laugh! And that's what I do! My friends tell me all the time how funny I am. I take a serious situation and make it funny. I think Victoria also got some of my wittiness! Having a sense of humor is one of my qualities.

I also have what I called my genius moments of FAS. It could happen any time. Or when I come with something witty. Like when I am doing one of my speeches. When the power point didn't work and Frances she looked at me and then I looked at her and I said "Well I am the handicapped one!" And everyone laughed so hard! So my FAS moments come out of nowhere (IT 2, pg 6)!

My FAS moments make people laugh. I can sometimes take things literally because of my FAS, but I can also be sarcastic. And I know that not a lot of people with FAS can be sarcastic! But like I said I am different.

I also like poems and stories. I think it's a way to understand people better and their lives. I want to share with you one of my favorite poems. I can really relate to this as I have had many workers in my life. I think this poem, is me on paper. It says:

If you are going to help me please be patient while I see if I can trust you.
Let me tell you my story, my whole story.
Please accept that whatever I have done or whatever I will do is the best I can do.

I am not just a person, I am unique.
Don't judge me as right or wrong. I am not bad or good, I am what I am. And that is all you've got.
Don't assume that your knowledge is more accurate than mine, you only know what I have told you and that is only a small part of me.
Don't ever think you know what I should do. You don't.
Don't place me in a position to live up to your expectations; I have enough trouble with mine.
Please hear my feelings and listen to my words. Accept all of them, if you can't how can I?
If I can't do it myself, I know enough to ask for help , now help me help myself (IT 3, pg. 4).

This poem reminds me of me. It's really me. Especially the part where they talk about people, workers, thinking that they know more than you when it is things that are happening in your own life. It reminds me of how they judged me as a mom, from the very first day.

It brings me back to the day I had Victoria. When I held her in my arms for the first time. And I had the workers watching and questioning me.

And I told them, I don't even know my baby and you think I am going to hurt her ? Why are you judging me, why don't you take her away from me if I do something to her! They said to me what makes you think that you can do this? And I said well what makes you think that we would be able to do anything? I said I am going to make mistakes, it doesn't mean I am doing it on purpose (IT 3, pg. 3).

This is one of the things that I cannot change, what happened in the past. But I can change what happens in the future and create a good relationship with my daughter. Together we can create our family.

And I want Victoria to have a family one day. I want her to know what it's like to have her own child. To hold her baby in her arms. But I want her to have it differently; for her not to have to fight to keep everything or to get everything.

And there are some things that I want her to take from our little family; our team. And I want her to know that families they can all look different. All families need help in different areas it doesn't make them bad (IT 3, pg. 4).

It makes them a family.

4.8 Cheyenne's Story

Nobody has been interested in what I have to say, no one has been interested in my story. I don't only want to be judged by my past. I have changed a lot and things are different (It 3, pg.9).

My name is Cheyenne and I am single mom who is Trini-Indian. I am 21 years old. I have a son Tyrone, who is 3 years old. He lives in a foster home. I have weekly supervised visits. I have never missed a visit with him.

Starting Over

*Child welfare has been involved in Cheyenne's life since the day she gave birth to Tyrone. Cheyenne recounted the difficulties she had in dealing with child welfare, particularly going to court every year. The last time Cheyenne went to court was a few weeks before our final interview***.**

When I went to the court, the last time, the judge he shook my hand. He told me that I was a good mom, because instead of fighting I just let things happen. And this time I said well I rather him be there because he can't be with me, obviously. So I'd rather him be there then be in limbo land. So the judge was happy because I decided to keep him there and not fight him. So he figured I was a good mom because of dat (It 2, pg. 5).

Ever since my son Tyrone was placed in foster home with youth protection, I have been going to court. He was a few months old when this happened. Every time I would go to court I would be angry. They would say things about me that weren't true! They would write things about me that weren't true! And I didn't agree with what they were recommending. Especially the first time the youth protection worker said that my son should go to a foster home because I was unstable. Sometimes I would stand up in court and yell. I was just so upset that they had my son.

But the last time I went to court, I was a bit different…

That day when I didn't fight I knew the judge will not put him with me, not give me full custody, so why what is the sense in fighting it? So I figured instead of making things worse I would shut my mouth. Nothing would change. He would not be coming back to me (IT 2, pg. 5).

I knew that he would not be coming home with me.

Not now anyway, I am not stable you know. I am not able to take care of a child right now. Why am I not stable? Well, I don't have a lot of money right now. I don't have a job. And I can hardly take care of myself, how am going to take care of my child, my son? That ain't fair for him. I am struggling to eat right now it would not be right to bring him into this situation (IT 3, pg. 4).

I am also on medication for my moods. Right now I take them but sometimes I don't. When I don't take my medication, I fly off the handle a lot quicker. I can lose my temper easier. Not usually with my son, but people around me. Like my mother or sometimes workers.

I have lost it with youth protection workers; they even had to call the cops once. They had changed a visit with my son and they couldn't reach me. I had taken a bus for hours, bought Tyrone a toy and some snacks and when I got there they told me Tyrone wasn't coming. I started screaming and swearing and throwing stuff in the reception area. I really wanted to see my son that day.

So I knew that if I wanted to have more time with Tyrone that I would have to do it this way. So I agreed with them. Or maybe I just didn't fight. My mom always taught me to fight. We always had to fight to get what we wanted or needed. Or at least it felt that way.

A few weeks after that court date, we received the judge's recommendations…

And the social worker she said to me because the judgment came in that I have all my parenting rights. He would not ever give me those if I would have kept going in the way that I did. So if he goes to school and he has a field trip then I have to sign. If they go away out of the country they have ask me my permission. So those things I still have. I am still his mother (IT 2, pg. 8).

I have mixed feelings about what the judge said. I sometimes wish he can be with me. I wish I could be with him every day. But a part of me knows that he can't be. I just hope they will one day, give me more time with him. And maybe when he's 18, he will come live with me.

A good life

I just want my son to be happy. I used to fight youth protection because I was really hurt and afraid. I didn't want him to love the foster family more than me. And after a long time, I understand that he loves those people. So I can't really say much. They take good care of him. They spoil him too much. But I am just happy that he is happy (IT 3, pg. 3).

They also give him a lot of things. They have a nice big house. With nice cars. The take him on vacation to the Dominican. They bring him to private therapies. There is a lot that they can give him. Things that me and family can't.

There is one thing that bothers me sometimes. Tyrone's foster family is white, white Canadian. And they speak more French. And he is black. Sometimes I think that he is living the white life. I mean they have all these nice expensive things. A fancy house. Far away from where he is from.

I think it's important for him to be around black people. Or people like him so he does not feel like an outsider. I felt like an outsider growing up and that felt bad. So it's important for him to be around people like him. So that he can say I am not the only one (IT 2, pg. 7).

It is also hard to take care of black kids' hair if you're white. But I still think that they care for him. Like he is their' s. I used to make a really big deal out of them cutting his hair. It was not because they wanted to cut his hair, it was because they could do it and that they were so close to him. Because he is not close to me like he is close to them. He knows that I am his mother don't get me wrong, but he is not close to me like he is to them. And that makes me cry (IT 3, pg.5).

I just don't want him to have to grow up like I did. He does not deserve that. Once you grow up in the hood, you can't get out. It's like a disease and it's hard to get out (IT 2, pg.4).

There is so much that I saw in the hood. Things that children probably shouldn't see…

Growing up in the hood

I won't lie. We were poor. We were. Sometimes my mom would not be able to eat because we had to eat. She used to make sure we had food. If there was anything left over then she would eat.

When I was young, I don't think that I knew that we were poor. Everyone around us lived like us. My mom would also buy us nice clothes. But I knew my mom worried about money. And I knew that it was sometimes hard to pay the rent.

It wasn't until I went to Summit school that I knew the difference. Between kids that are poor and kids that have money. Kids would come from all parts of Montreal. Not just where I lived. And because it was a special school, they took kids from everywhere.

But yeah, we grew up poor. And like I said my mother sometimes she would not eat. That's one thing she was a good mother for that. She always found a way to put food on the table. Even if we had only a little to eat, she would make something out of it. She is very creative. That's where I learned my creative cooking skills (IT 1, pg.5).

We always had what we needed. But it was hard. My mom raised us on her one welfare check. About 600$ plus child tax benefits a month. No money from my father.

The neighborhood that I grew up in, St-Henri, is a rough neighborhood. Most people live in public housing. It doesn't seem like it is but if you are there long enough you will see people with guns. Crack heads. Whores walking up the street. I grew up with that stuff. You know with all those crazy people doing crazy things. I grew up also hanging out with them. But I am trying not to anymore because I don't want Tyrone to be around that and become like that (IT 1, pg.5).

It's weird because youth protection said that the neighborhood that I lived in and the people that I was hanging with were not good people for Tyrone. They said that I was with Tyrone in my apartment with people that hand guns and knives and they were in gangs. That's not true! They might look like they were in gangs, but they were not!

Do you think I would do that in front of my son? I think Batshaw {youth protection} is a bunch of chickens. They know where I come from and they are scared. I just think they are blind. They only see what they want to see (IT 2, pg. 5).

And what they wanted to see is that I am a bad mother. I am a bad mother because if where I live, how I grew up and who I hang out with…

But what they don't understand is that even if I don't hang around these people, we will still be a part of the gang life. Once you start in it that's how you are known.

But I don't want them in my life no more.

I think it's hard to get out of living that kind of life. The ghetto, the hood, the gang life. But I think that it can be different for different people. There are people from different countries here too.

And different cultures have different beliefs. Different ways that children are brought up. No matter if you live in the ghetto you can still have a good life if you were raised properly with good values (IT 2, pg. 6).

I remember this family near where I lived that were Muslim, I think. The parents had rules and the children would always listen. All these kids were raised in the ghetto and some were well behaved. And there are some that became these savage beasts. Cussing and swearing.

It also depends how long you stay. Some were good kids when they were younger. And now they are shooting people, killing people too. And they are drinking, smoking, doing crack. Trying to make money.

And if you think that you are going to get out, and go somewhere else, then maybe you have a chance for living a different life with your children (IT 3, pg. 4).

Feeling different

I grew up with my mom and my older brother. My parents were not together. All her side of the family was all racist so I never really kind of fit in with them (It 1, pg. 1).

I also have a younger brother and a younger sister.

When I was younger I was the only one with darker skin. My mother is white. My brother is white. We had different fathers. My father is Trini Indian.

My mother's father really did not like me. I think that he wanted me gone. Because I am not white. I used to hear him talking about me. He would say that I was dirty. Because of the color of my skin. I used to ask my mom why I didn't have the same skin color as her or my brother.

She never answered me.

I think my mom felt bad about what her family put me through. How they ignored me. How they insulted me. So she bought me a lot of things. Don't ask me how she did that because she had no money. Maybe it was her sugar daddy. He used to come by the house, hang out and give my mother some money. We used to joke and say he was her sugar daddy, because he was a lot older.

I think that made my older brother angry. That I would get special things. Maybe that's why he would cause a lot of trouble at home. He would set things on fire and was just a lot of trouble.

So when he got into trouble, then my mom paid more attention to him. So I started to realize that he got more attention…

I decided to be bad like him at around 12 years old after *what the thing that happened*.

I started lashing out more, getting into trouble. That's how I ended up in Summit getting into trouble. Beating up kids. I split a girl's lip open because she called me a nigger. This is how it happened, she said "you're ugly". And back then I was skinny so I said thank-you. And she said "oh no you are a nigger". I said what? Excuse you? And then I pushed her into the chalk board and she spilt her lip open. And that's how I ended up in Summit. No one else wanted me after that (IT 1, pg. 5).

The thing that happened

Not many people know about what happened to me. It's really hard to talk about.

I was about 12 years old at the time…

One weekend when I visited my dad. It happened. It was something that I did not think would happen. I didn't want it to happen. But it did. And I didn't tell anyone, not even my mom.

But I wanted her to know. I kept telling her that I didn't want to go back to see him. I went into a shell. I was in my room a lot more. And I was very upset.

After what happened, anger was what I let everyone see.

And once I started getting the anger, the anger started burning up inside of me. Because I never told anybody. And then I started lashing out at everybody (IT 3, pg. 4).

And now I am starting to deal with it better, but back then when I was younger nothing mattered. I was angry at the whole world. And it didn't matter what anybody said or if someone did anything or not, I would be rude.

But now I know that it is not the way to go but back then it was my life and I didn't give a fuck what happened. What anybody said (IT 2, pg. 3).

The thing was when I was acting out, I was looking for her. To be there for me. Not to punish me. Not to beat me and send me to my room. But to ask me what happened? What can I do to make it better?

But she didn't do that. She didn't do anything!

Where is her mothering instincts? She should have known! And I mean if she could have caught my brother smoking outside the window she should known that my daughter has been raped (IT 3, pg. 4).

I think she was trying to ignore it. Like it didn't happen. But I couldn't ignore it. And I was trying to get her to see that I wasn't ok. That I needed her.

This is when I really started to get out of control. My behavior was out of control. My mom couldn't handle me. That's how I ended up in a group home. I was in and out of the group homes from the age of 11-12 years old. I would go there for a few months and then come back home.

It was like that for me and my older brother. It was also like that for one of my younger brother's Roshand. I hated being there but I also hated being at home.

Them in my life

I had them in my life for most of my life. Batshaw. Youth protection. I don't know why they call them that because they didn't protect me. They didn't even try to find out why I was acting the way I was.

They just put me in a group home with these other girls that had behavioral problems. The good thing is that I was still going to Summit school at the time so at least that was something that was familiar to me.

There were a few teachers at Summit that were like family to me. There was one teacher that bought me cigarettes and would bring me to her house. She was like my mom. I felt like she cared for me. When I feel that a teacher, a worker, actually cares about me, I respect that much more. I won't usually fly off the handle with them.

And youth protection are back in my life; that makes me upset. They are an uninvited guest. I wish they would leave me alone. Leave me in peace. But I know they won't. Once they are in your life, they never leave. Once they are in a family, they are always watching.

The difference between me and my son is that I was in and out of group homes and he will be in one foster family until he is 18. At least he does not have to put up with what I had to put up with. All these workers. In and out. It will just be his foster parents. The social worker. And me (IT 3, pg. 5).

True Colors

I remember when I was younger than even with what happened with my dad that I was closer to his side of the family. I don't talk to my father, but I am closer to his side of the family. Because they all accepted me and know who I am. Because I look like my dad's side so they know I look like my dad's kid, you know. They accepted me good and now they askes me what culture are you, I say I am Trini Indian I don't say I am white, I don't say I am black, I am Trini Indian (IT 1,pg.1).

I grew up in my house and looked like no one. I was also treated badly by my mom's side of the family. That made me closer to my dad's side.

My father's mother she was good to me. I would go to her house, sometimes, on the weekend. She was always cooking. She is the one that taught me to cook. Like Trinidadian style.

She would cook in front of me and try and show me things. Like how to make Roti and how to make Polari's. I was only 7 or 8 then. So I was young.

I wish I could remember everything that she taught me. So that I could make it for Tyrone one day. But I am a good cook. I can make some really good things. I also use a lot of Indian spices.

And I call my grandmother, mom. In the Indian culture we call our grammas mom. I am closer to her than my mom's mom. My mom's mom she is a crack whore, or used to be one though she says she does not do it anymore (IT 4, pg. 7).

I remember my mother's mom taking food from me when she was high. She knew that my mom had sent me to the store and would find me. She would take some of the stuff I had, for her. She probably spent her money on crack.

I see my father's mother a few times a year. Sometimes I will go and see her at her restaurant. My grandma and aunt own a Trini restaurant close to downtown. The food is so good there.

People say that I have a disability.

I don't really think I have a real disability. I hate that word. I hate it when I feel "retarded". When people make me feel that way. When they make me feel that I can't do something and that I need to have help (IT 4, pg. 6).

I did go to a special school but I think it's because no one else would take me. I was getting into a lot of trouble even at school. I don't think my other school could handle me so they sent me to Summit. That's where they send all the kids who have behavior problems.

But it was weird being at a special school, especially at the beginning. I feel awkward because everybody was always looking at me. And I thought oh my god I am going to die? It was all retarded people, they were all retarded, what I'm I doing in this school with all these retarded kids? But after for the first year, it was ok and everyone was pretty nice with me (IT 2, pg. 3).

Because I had more skills then the other kids, I would also help out a lot. I would help in the office. I would help bringing and getting things for teachers. I would help with petty cash. I even helped with the kids at summer camp.

I am actually pretty good with math. I was never good at English, French, and writing but I got by. But no one in my family is good at school. No one finished high school. Sometimes I think I should go back to school. See if I could get my high school degree. But I am not sure that will happen.

Summit school made a referral to the readpation center. When I was younger I went to some groups. They helped with my anger.

I still receive some help from the readaptation center. I see my educator and other people at the center. I find it hard sometimes because they can be busy. And they have so many clients. I don't really think of them as help, they are a part of my life. They help me with some things in my life. They talk to me when things get out of control. Sometimes I take their advice. Sometimes I pull away.

Life with Tyrone

I was 18 years old when I got pregnant with Tyrone. Jason is the baby's daddy. We were together for a few months when I became pregnant. Jason and I did not plan it this way. But it happened. And I knew that I wanted to keep him.

Giving birth to Tyrone was a blur. I remember that it hurt a lot. I remember that Jason was there. I remember my mom being there too.

At the hospital, I felt like I was doing things well with Tyrone. I was walking up in the middle of the night to feed him. I would change his diapers. I would hold him. I felt like a good mom. After all, I took care of my younger brother and sister.

Back to the hospital.

I did feel like the nurses were looking at me funny. And I was right. I think they had it in for me from the start. Was it because they thought something was wrong with me? Was it my skin color? Was it because of where I live? Was it because my family is on welfare? (IT 3, pg. 6).

I still don't really know the answer to that…

And then we were getting ready to leave and um well they figured out my routine. I would wake up and have a cigarette and when I came back to get Tyrone I asked where my son was. And they says to me he is in the nursery with the police and Batshaw workers. Um like what, I want my son and I was going crazy. And I almost punched the Batshaw worker. They had to hold me down. And I called my mom and told her that I was going to kill somebody!

And my mom said let them take him and they we will take or get him back. And I started flipping out screaming "no they are not taking my baby. It's my baby"

I was throwing things and stole everything in that room. I took the towels, the clock on the wall. If they wanted to take my baby I was going to take their stuff (IT 4, pg. 8).

They took my son away and put him in a Batshaw home. I didn't eat for days. People had to force me to eat because I was breast feeding. I stayed in my room and cried all the time. Just barricaded myself in the room. And Jason was nowhere to be seen. He didn't care. I got into a fight with Jason and he left and never came back. And I was like he didn't want to be a father so that's fine with me (IT 4, pg. 8)! And then 12 days later, the judge decided that my mom could have custody of him. For about a year and then we would have to go back to court.

Things were going good the first few months with me and Tyrone at my mom's. I would do everything for him. I would even take care of my younger brothers and sisters. My mom has a heart problem and she is very tired. So I would take care of the kids. After a few months, me and my mom were starting to fight again like we did when I was younger. And I didn't think it was good for me to stay there with her and my son.

So I got a place close to my mom's. She was supposed to have custody of him and I could take him on the weekends. But what Batshaw doesn't know is that I would bring him all the time to my apartment. I would take him for as long as I wanted. Until Batshaw thought that he was in danger. And then they took him away for good.

But that's the past and I don't want to remember it.

But I still have chance now to make it up to him. At least he still knows that I am his mother and I am there every week and I see him every week, they can't change that. He knows who I am and they can't change that. They can't adopt him. I will always be there in his life (IT 4, pg. 4).

When I visit Tyrone, we play together. Sometimes we go to the park. We go see the animals at the pet shop. We play basketball or play in the sand box. I throw him birthday parties. And we have fun.

I hope that his story, Tyrone's story, will be different. And that he knows that I tried to change for him.

CHAPTER 5. STUDY FINDINGS

5.1 The Poem: We are Mothers

We are women who belong to a cultural community.
We are Portuguese, Native, Indian, Polish and Chinese.
We have gone through ups and downs in our lives.
We have been taught that family and culture tell us who we are and how we should act.
We have been called ‘stupid’, ‘lazy’ and ‘dumb’ by important people in our lives.
We have been told what a good woman is and is not.
We have tried to play the role of the ‘good girl’ that we were cast to play in.
So that we can be ‘normal’;
So we can fit it;
And bring pride to our family.
We have experienced what it is like to be different,
To feel like we do not belong,
Because of who we are.
We have married and had children.
This has brought us the most joy:
Being a mother.
We have had our ups and downs.
We have battled abuse, rape, poverty, divorce,
And had our children taken away.
But we do not give up.
We have not let other people’s words, ideas and actions define who we are.
We question some of the values that have been enforced on us.
We resist some of the actions that have been imposed on us.
We have re-defined who we are,
So that the world can see:
We are women, from cultural communities, that sometimes have disabilities.
But most of all, we are mothers.
(Pacheco et al., 2011)

5.2 Narrative Threads

Figure 2 Summary of Narrative Threads

Narrative Threads Mother	Loss of a loved one	Loss of country of origin	Abuse in childhood	Abuse from partner	Expected to be wives and mothers	Asked to keep social failings a secret	Called names when didn't meet expectations	Isolated from family when didn't meet expectations
Harrah	X	X		X	X	X	X	X
Maria	X	X		X	X	X	X	X
Halina			X	X	X	X	X	X
Pria			X	X	X	X	X	X
Dung		X		X	X	X	X	X
Mary	X		X	X			X	
Sheira			X	X			X	
Cheyenne	X		X	X		X	X	X

Figure 3 Summary of Narrative Threads

Narrative Threads Mother	Physically punished when they did not meet expectations	Disability seen as a negative identity by family	Used own words to define themselves	Questioned cultural traditions	Questioned unequal power relations	Took action against unequal power relations	Mothering seen as most important identity
Harrah	X	X	X	X	X	X	X
Maria	X	X	X	X	X	X	X
Halina	X	X	X	X	X	X	X
Pria	X	X	X	X	X	X	X
Dung		X	X	X	X	X	X
Mary			X			X	X
Sheira			X		X	X	X
Cheyenne		X	X	X	X	X	X

5.2.1 Loss

Embedded within the life stories of these eight women is loss. These women had important things and people taken away from them at different moments in their lives. Four of the women in this study were born in their country of origin including Portugal, India, Vietnam and Trinidad. These women continued to call their country of origin their home, even years after they left. Leaving their country was a significant loss for these women. Their home (as these women put it) signified stability, predictability, and closeness to their family, friends and community. These women looked back on their childhood in their country of origin and reminisced about when times "were good and easy" (Harrah, IT 1, pg.4) and where they felt they had a place in their family. Their disability, for the most part, was not something that was talked about when they lived in their country of origin and they did not feel as though they were different. Conversely, three of the mothers that were born in Canada, discussed how they felt different in their family and many of them attributed this to having a disability.

For the three mothers who immigrated, coming to Canada was marked by mixed emotions. On one hand, these women were leaving what they knew and loved; their homeland, their family and their traditions. On the other hand, they faced the promise of a new land that could take them out of poverty and provide their family with a better future. All of the women who immigrated to Canada at a young age had never gone back to their country of origin but hoped to bring their children there one day. Many of the women thought that by going home, they would "be away from the problems" that they encountered in Canada like the couple conflict and child welfare issues.

Four of the mothers also lost important people in their lives. These people were important to them because they felt that they could go to these individuals when they needed comfort or advice. As Mary put it they felt that these family members were "the only ones that were there" for them (IT 2, pg.5). The women recounted how these family members helped them through the loss of a loved one or were there for them when they needed to talk to someone when they had a bad day. These family members included an older sibling, a grandparent and a parent. Thus, when they lost these important people, they often lost 'the one who cared' (Mary, IT 2, pg. 5).

The lives of many of the women were not only marked by the death of their loved ones; they did not have the opportunity to grieve their losses by participating in traditional ceremonies associated with the passing of a loved one. For some of these women it was because they lived so far away at the time of the funeral and the family did not have the monetary means, which would allow them to go back to their country of origin. For others, the decision was made for them that they could not handle going to the funeral.

All of the women in the study except one experienced the loss of their children, either temporarily or permanently, within a child protection context. Their children were placed in foster care and for one mother in this study two of her children were adopted. None of these mothers were in agreement with their children's placement and/or adoption at the beginning of the child protection process. This increased their pain and feelings of powerlessness. The immense pain associated with the loss of their children ran deep into these mothers' life stories. They described both the initial loss of their children when they were first taken away and the loss they felt every day that their children were not in their home with them. When they shared this story, the emotional wounds that were associated with their children being taken away (for some 10 to 20 years later), were as raw as if it happened yesterday.

Some of the mothers discussed the lack of support given to them when their children were taken from them. A few of the mothers described how their loss was not understood or how they were not encouraged to grieve this loss. They felt as though their family, neighbors or workers didn't really care, 'no one knows how I am feeling' as they did not ask how they were doing or if they wanted to talk about it. It was as if they were supposed to just forget about the fact that their children were taken away.

5.2.2 Abuse

Another striking feature found within these women's narratives was the abuse imposed on them by important people in their lives. This included emotional, physical, sexual and financial abuse. Four of the women in this study were abused by members of their family when they were children. These women were sexually abused by their fathers and step-fathers; called names by family members; exposed to conflict between their parents; and, experienced physical violence. Many of the women described this abuse as a result of who they are, as Pria stated ‘I think it’s because I was slow’ (IT 2, pg.2). Pria was able to come to that conclusion as she did not see her sister, who lived in the same house as her, go through the same type of abuse as she did as a child.

None of the women who divulged abuse within their family of origin were believed. Some were blamed for what happened to them. Maria, Pria, Cheyenne and Sheira’s allegations of abuse were not believed or taken seriously by their family, police or the school system. These women suggested that people did not believe them because they had a disability:

When I said what my dad was doing she (my adoptive mother) turned around and said that I was lying and that it never happened, and I was the one that came on to my own father. And the police believed them because of the FAS (Sheira, IT 1, pg. 9).

All of the women in this study were abused by at least of their partners when they were in relationships. They were denigrated, ‘beaten’ and forced into sexual acts:

And then he pushed me on the sand underneath the stairs in the basement and he was saying bad things to me like bitch, whore, and things like that. And I told him not to call me that, that I was not that. And he told me that he wanted to have sex with me and I told him that he was not going to touch me. But I couldn’t do anything, he was stronger than me’ (IT 1, pg. 5). He tore off my clothes and he took off his clothes, you know the way he made love to me, it was not love. It was like rape. He was on top of me and forcing himself on me, I told him to stop but he didn’t care. He didn’t stop. The more I told him to stop, it hurts, and the stronger he got on me. He was on me. I was dying for him to stop. I was dying for someone to come home (Maria, IT 1, pg. 5).

The abuse these women experienced was difficult in the moment and had a lingering affect in their lives. Some of the women believed that they deserved the abusive treatment they were receiving. These women internalized what their partners were saying about them. Others were able to see the abuse as abnormal, as Maria put it “I am not an animal”, and they fought against it in order to end the abuse for themselves and their children. Many of the women did a little bit of both, at different times in their lives. Many of the women were able to end their abusive relationships when they had “had enough”. For some of them it was when the abuse turned to their children or when they realized that they did not want their children to live the life that they had lived and experience the pain that they went through.

Many of the women saw the impact of the abuse on their children. They all agreed that their children's exposure to the abuse was harder on them than the abuse they had endured themselves. A few of the mothers tried to "keep quiet" when they were being "beaten" (Harrah, IT 2, pg. 3) in order to try and prevent their children from being exposed to the abuse. Each of the mothers tried to protect their children from their abusive partners. They did this by trying to distract their partner, by telling their partner not to touch the children, and by telling their partner to hurt them instead of their children. For the most part they succeeded, except on a few rare occasions:

She used to cry in the middle of the night and he would scream at me, to tell her to shut up, you know. I would tell him that this is what babies do. One night when he came home and he was trying to fall asleep, Mary started to cry. He told me that if I didn't find a way to keep her quite then he would do it. I was rocking her in my arms and she was still crying. He had those anger eyes and he came towards me. He grabbed Mary and threw her. Her head ended up hitting the bed board. She stopped crying (Maria, IT 2, p. 8).

5.2.3 Turning points in their lives: getting married and having children

Expectations of wives and mothers

From the time that they were little girls, more than half of the women in this study knew that they wanted to get married and have children. This was important to them, to their families and cultural community:

In my culture. Yeah, that's what the women do. They get married and they have the children. If you don't have babies then you always live at the home with your parents. Very important thing I knew I wanted to have kids (Harrah, IT 1, p. 3).

These five women learned quite early on what it takes in order to be seen as an ideal wife and mother. However it wasn't until they entered these social roles that they understood what was really expected from them. They learned that good wives were those that took care of their household by keeping it clean and organized. Good wives were those that kept their husbands happy by making the meals and "acting in the way that they should" (Harrah, IT 3, pg. 3). Good mothers were those that took care of their children, always putting them first. These women also had the role of making sure that the family image was maintained. This meant that they had to conceal anything that would make the family stick out in a negative way. This included having to hide couple conflict, abuse, and their disability. They had to deal with and or hide personal and family issues in order to focus their energy on maintaining a proper family image and keeping their family intact. Thus, keeping their family together was vital, no matter the circumstances. From the perspective of their family and cultural community, abuse and spousal conflict were not grounds for divorce. The women that experienced abuse by their husbands were asked to remain together as getting a divorce has a negative impact on the family's and community's reputation:

I can't divorce him because I have three children. Even if he does not treat me right I still have to stay with him. Because my culture, won't let me divorce him. Because if I divorce him then I feel ashamed. My family ashamed. I feel bad. I feel like I was a bad girl because the marriage don't work (Dung, IT 3, pg. 4).

Motherhood, most important identity

Though some of these women experienced the pressures of being a good mother and wife, their role and identity as a mother was seen as 'the most important thing' in their lives. They held onto this identity no matter where their children were living. All of these women discussed the 'joys and heartaches' of motherhood (Booth & Booth, 2000). Maria and Harrah both describe the overwhelming feelings of joy in finding out that they were pregnant and the day their children were born as "the best day of my life".

Motherhood would become the role that defined all of these women. Maria asserted that "Being a mom is everything to me". Similarly, Harrah noted that "I am nothing without my children", and Halina stated "they are my life". It would become a role in which they felt the most empowered. It became the role where they would be able to give and receive unconditional love. Harrah, Dung and Maria described their entry into motherhood as also increasing their worth within their family. Maria, in particular, described how she felt like she belonged when she was pregnant and had her baby. Her family was there to support her. Motherhood brought a renewed sense of belonging. The family would see Maria positively when she became a mother and 'performed mothering' as if less desirable parts of her identity disappeared, such as her intellectual disability.

Their mothering role changed when their children were taken from them. However, their focus on their children never wavered. Maria, Cheyenne and Sheira described how letting their children go could give them a better life. Maria, Cheyenne and Sheira described this as a process, as they initially had tremendous difficulty letting their children go into placement but eventually saw that their children were doing well. This was important for these mothers. This enabled these mothers to see that the placement of their children wasn't entirely negative as their children seemed to benefit, at least in part, from their placement:

… I just want my son to be happy. I used to fight youth protection because I was really hurt and afraid. I didn't want him to love the foster family more than me. And after a long time, I understand that he loves those people. So I can't really say much. They take good care of him. They spoil him too much. But I am just happy that he is happy (Cheyenne, IT 3, pg. 3).

For the women in this study, their mothering role was identified as their most important social role. Their mothering identity was something that they never gave up, no matter how much time ticked by, no matter what happened in their lives. Their role and identity as a mother was not taken away even when their children were taken from them. This was something that they held onto and would never give up.

Being a mother was always something that I wanted. Something that I dreamed about. No matter if I don't see them every day; I am still Mary and Manuel's mother. I am always their mother (Maria, IT 7, pg. 9).

Not living up to expectations

The majority of the women in this study were not only able to identify what it takes to be a good wife or mother, they were also able to identify the consequences of not living up to cultural and social expectations. There were different repercussions for not meeting these standards. The first consequence was that they were asked to keep their social failings a secret. They were asked to keep their circumstances a secret from extended family members, neighbors and persons within their community. This was asked of the women in order to prevent their family and community from being "shamed". This was described by Maria whose family asked her to keep the abuse (towards herself and her children) at the hands of her first and second husbands a secret from her extended family and community. Though Maria described abuse as occurring in her cultural community, it's not something that is talked about. It's something that you live with but that you do not get extended family or community involved in. And you certainly don't talk about the fact that you want a divorce. As a divorce is a "mistake", a "sin" and goes against "The Portuguese Way" (Maria, IT 1, pg.9).

The second way in which these women experienced the consequences of not measuring up was when they were told by their family and or cultural community that they were "not normal" (Maria, IT, 3, pg. 6). Many of the women were called "lazy", "stupid" and "crazy" by members of their family and community. This was usually because they were not doing or performing tasks as they "should be", or because they were exhibiting behaviours that did not fit the norm.

The third way in which these women experienced the consequences of not measuring up was when they were isolated from their family. Harrah described how she felt abandoned by her family because she was not like her brothers or sisters as she didn't have a house or car, and had visible "family problems" (IT 2, pg. 3). She felt particularly cast aside when youth protection got involved and questioned her parenting abilities, and inquired into the couple's issues and her husband's gambling problems. Her family questioned her 'womaness' as she was seen as not being a good mother. Her family also questioned her husband's 'manliness' because he was seen as not being able to provide for his family because of his gambling addiction. Maria also described being shunned by her family when she spoke out about the spousal abuse, when she wanted to get a divorce from her husband, and when she lost custody of her children.

The experience of denigration and or exclusion that these women encountered within their family and/ or cultural community impacted their sense of belonging. Some of the mothers felt as though they often didn't belong anywhere, especially when they were 'caught' not doing as they should. For the mothers that described their culture and family as one 'of the most important things' (Dung, IT 3, pg. 11), they often felt as though they were caught between social worlds, claiming that they didn't know where they belonged because of the rejection they felt from everyone and everywhere. For three of the mothers, it sometimes left them thinking about 'why I was even born' (Maria, IT 1, pg. 7).

5.2.4 Battling against authorities in their lives

The women in this study experienced unfair treatment by different people and systems in their lives, however, they did not become victims of their circumstances, they were able to, at times, fight against the negative forces in their lives. They did this by 1) identifying the negative perceptions people had of them as being unjust, 2) questioning the fairness of their relationships, and 3) taking action against the different authorities in their lives.

Confronting what others think

The mothers in this study were aware of how others viewed them as wives and mothers, which for the most part was 'not good enough'. Many of the women in this study described how their disability was seen as a negative thing; something which made them stick out in a bad way within their family and community. As Dung puts it, "*In my culture, people with the disability, they think they are sick. Or stupid… Because that make the family look bad.* (Dung, IT 3, pg. 9).

The women felt bad about the way in which others saw them, for example, being seen as "lazy", "sick" or "crazy". However, for the most part they did not agree with what was being said about them. They rejected the term "retarded" as it seemed to signify something they were not; incapable and dependent on others. Many of these women preferred to use the term "slow learner" to describe their intellectual disability. These mothers maintained that their disability was only a small part of who they are. As Dung (IT.1, pg.9) put it, "sometimes I think I have a disability and sometimes no". In other words, depending on what they were doing and who they were with, their disability was either minimized or accentuated. An example of how context impacted the way that these women were seen was when they first gave birth. In the eyes of many of their families and cultural communities they were highly regarded, however, from a system's perspective, their disability was often magnified and they were often seen as incapable. Some of the mothers were aware of how they were seen and treated differently and began to question the fairness of this treatment:

And I was giving them reasons to give me a chance! It was like it was an interrogation and I had to prove to them why I should be a mom. But the whole time I was thinking, you didn't give that lady who was on a crack a choice you just gave the baby and that was it! And it really complexed me, I hadn't done anything to my baby! I didn't go in there, slurring or high. You know I'm sitting there working it and pushing my baby out. And she made some horrible choices and she got to take her baby home. And what message does that send to me? (Sheira, IT 2, pg. 7).

The women also questioned the fairness of the arrangements within their interpersonal relationships. For many of the women they did this within their marital relationship. Harrah, Pria, Maria and Dung described their discontent with some of the ways in which their husbands acted towards them in their marriage. They did not feel respected and often resented having to do most of the tasks with the children and within their household. These four women were able to define their relationships as being unequal at times and were able to identify negative power relations.

Some of the women also questioned the cultural traditions that were enforced by their family members. Maria, in particular, questioned her family's insistence on having an abortion when she became pregnant after being raped by her first boyfriend. Her family declared that the pregnancy 'was not made out of love' and therefore, she should have an abortion under this circumstance. For Maria, having an abortion was not only a sin, it also took away the possibility of having a child, something that was sacred in Maria's eyes. At that time, as she was living with her parents, she decided that it was best to keep the peace and have an abortion. Maria described the courage it took to question her family even though she did end up having the abortion.

Some of the women went beyond questioning unjust treatment within their relationships and confronted their partners about how they felt the arrangements were not fair: *Now it's like he does nothing in the house, you know the cooking, cleaning and take care of the kids. I tell him that. I'm tired of doing it all the time* (Harrah, IT 2, p. 8). Maria, Halina, Pria and Mary also described how they took action against the unjust treatment they received including deciding to leave their husbands. They did this as they realized the negative impact the couple dynamic was having on their children and themselves. These women were able to take a stand, first by identifying what they felt was 'not fair', and then by taking action; leaving their husbands.

5.3 Understanding the narratives through an intersectionality theory lens

The women's lives, identities and experiences were influenced by the dynamic interplay of oppression and agency. The way in which social structures and cultural context shape and constrain the identity of mothers with intellectual disability was also described by Roets et al., (2008, p. 105) who explored Rosa's narrative, a mother with intellectual disability from Belgium. Roets et al., (2008) notes "Apparently she had all to soon been objectified, classified and devalued as other in terms of a grand narrative of deviance, lack and tragedy". The grand narrative of deviance, as Roets et al., (2008) describe, is a social script, where actors are given parts to play based on a particular storyline. If we apply this to the women in this study, the actors are the dominant culture and its agents of control (i.e. child welfare, schools), mainstream community members, cultural community members, and these women. The script surrounds the idea that women with intellectual disability from ethnocultural communities are given a role to play in order to be considered a "good woman". The good woman is one that abides by the rules that are set out for her and performs her role as a wife and mother according to these norms. Women who do not follow the rules or do not perform their roles adequately face negative reactions from the social actors in their lives. In return, these women can accept some of these rules or can reject some of the expectations and fight against the negative actions of others. The mothers in this study were able to express dissatisfaction with how others viewed them and what they expected from them, and proposed new ways of being seen.

In order to explore the ways in which oppression and resistance operated in these mothers' lives, intersectionality theory, more specifically, Collins (1990, 2000) Matrix of Domination was used to interpret the life stories of these eight women. This revealed the following:

- The messages received from their cultural community, family and society at large tells us about what it means and takes to be a good woman (*structural domain*)
- What life is like when you are seen as "not good enough": Lacking the power to influence destiny (*disciplinary* and *hegemonic* domains)

- Resisting negative messages and or actions (*interpersonal domain)*

5.3.1 Messages about what it takes to be a good woman

The structural domain refers to ideas that are found within social and cultural contexts that influence the way in which people interact with and treat persons who occupy inter-related social identities. The women in this study had to deal with multiple and often conflicting messages from their cultural context (society and cultural community) about being a woman and mother with intellectual disability.

Messages from cultural community about motherhood

Five of the mothers in this study were encouraged by their family and cultural community to marry and have children. When these women were young, they dreamed of getting married and having children and were encouraged to take on this role. Some families went so far as to choose their partners in order to ensure that they fulfilled these roles. As many of the mothers explained, getting married and having children represents "what women do in my culture" (Harrah, IT2, pg.2). This cultural socialization towards marriage and motherhood conflicts with the messages that they often received from mainstream society (which will be explored in more depth in the next section). Furthermore, this socialisation sets their experience apart from mothers with intellectual disability who are members of the majority culture. Booth and Booth (1994), for example, found that many of the mothers in their study were discouraged from having children and were pressured to have an abortion by their informal and formal social networks. They contend that this pressure was due to the assumption that persons with intellectual disability could not be good parents.

In contrast to the mothers in Booth and Booth's (1994) study, most of the women in this study were taught that a woman's most important role is as a wife and mother. Their families supported them in achieving these roles in order to become respectable members of their community. Some of the women's families even thought that if they got married and had children of their own that they could become "normal" and that their disability would disappear.

Once they got married and had children, four of the mothers were seen as wives and mothers and not women with intellectual disability. Their disability was overshadowed by their wife and mother identities especially when they performed their roles in accordance with the standards that were set out by their family and cultural community. This will be further explored in the section on *hiding parts of self in order to save face*.

The messages that these women received from their ethnocultural community impacted the way in which they saw themselves and how they made decisions in their lives. Though many of the mothers sometimes had mixed feelings about their cultural community and their family and the control they felt they had in their lives, many of the mothers felt that "family and culture is the number one thing". Collins (1990) expressed the positive and negative features of cultural and racial communities within her intersectionality theory work. In one way, Collins explains that cultural communities can provide a buffer to oppressive ideas and practices held within mainstream society, and in another way cultural communities can perpetuate power imbalances. There were times within the women's narratives where they received conflicting messages from different contexts and they felt caught between different ideals. Maria, for example, described her struggle to reconcile her religious values and her personal beliefs, as she was brought up in a traditional Portuguese Catholic family. She described getting pregnant after she was raped by her first boyfriend and her family's insistence that she abort the child 'because it was not made out of love'. Maria was caught between her parents' authority, cultural expectations, and her own desire to have children. Having an abortion seemed to symbolize breaking cultural and religious norms and threatened her desire to have children. Björnsdóttir and Traustadóttir (2010) illustrate the influence of religious institutions within their intersectionality study, "Religious institutions, alongside educational institutions and the media, have control over the ideas and knowledge that reinforce and reproduce the existing social hierarchies of class and gender among others. Religious institutions control the ideology that supports and justifies the interests of the dominant group" (p.59). We see how Maria, Mary and Dung's narratives, in particular, illustrate how they question and confront religious, cultural and familial ideals in order to create their own standards.

Messages from mainstream society about being a mother

When these women became mothers, their intersecting identities, as a woman with intellectual disability and as a mother collided. Stereotypes surround both of these social locations; ‘good mothers’ are constructed as nurturing, selfless, financially stable and sufficient for all of their child’s needs (Davies, 2008). By sharp contrast, the stereotypic person with intellectual disability is one that is incapable and is dependent on others in order to live their daily lives (Booth & Booth, 1994).

What many of these women faced, from the beginning of their mothering experience, was the assumption, on the part of professionals, that they were unfit mothers because of their disability. This assumption of incompetence has been well supported in the literature (Booth & Booth 1994, 2000; Booth & McConnell, 2005; Mayes, Llewellyn & McConnell, 2006). As many of the mothers in this study pointed out, as soon as they became mothers they felt as if, ‘they had it in for me from the start’ because of their disability (Cheyenne, IT 3, pg.6). Cheyenne describes how she felt observed at the hospital after she gave birth to her son:

I did feel like the nurses were looking at me funny. And I was right. I think they had it in for me from the start. Was it because they thought something was wrong with me? Was it my skin color? Was it because of where I live? Was it because my family is on welfare? (IT 3, pg. 6).

Cheyenne’s quote also represents her attempt to understand which part of herself was the cause of these negative preconceptions. From an intersectionality perspective, there can be a part of an identity that becomes more vulnerable to oppression within a certain context. Three of the mothers in this study also discussed the ways in which they felt targeted because of their intersecting identities (gender, disability and culture). They described being called derogatory names not just in regards to their disability, but also in regards to their ethnicity, for example, being called “a stupid packi” (Pria, IT, 2, pg.4).

Seven out of the eight mothers in this study described being trapped in the child welfare system; a common experience of mothers with intellectual disability (Booth & Booth 1994, 2000; Booth, Booth & McConnell, 2005, McConnell & Traustadóttir, 2010). Having intellectual disability and being a mother places them at a disadvantage. They described being unfairly investigated within the child welfare system as a result of their disability. Many of the mothers described how they were solely blamed when there were any difficulties in their family life. Their narratives also seemed to reveal the concept of ‘mother blame’. Davies (2008) further describes ‘mother blame’ as deriving from the societal expectations that mothers are to be completely devoted and responsible in meeting all their children’s needs and are held to be solely responsible when their children, family, or environment are not up to par.

Messages about having disability

These women also received messages about their disability. When these women were doing, as they should, that is fulfilling their roles as daughters, wives and mothers in accordance with the cultural expectations, their disability seemed invisible. Their disability became a “bad thing” as Dung put it, when their disability negatively impacted their ability to be a good wife and mother. This is when many of the women were called names, were told that they were “good for nothing”, were ignored by family members or became victims of physical abuse. Hepper (1999) reports similar findings in a case study of a woman with intellectual disability in the United Kingdom who was born in Bangladesh, and who suffered spousal abuse when she was not able to perform household duties appropriately.

These women also discussed the impact the disability has on the whole family. Their disability was seen as ‘marking the families as bad’. In others words, not only were these women told that they were not good enough because their disability prevented them from doing what was expected of them, it also had an impact on their family. Their families were not able to keep up with appearances because one of their members had a disability. Therefore, for some these women were not only labeled as “bad” they also had to carry the burden that their family was seen in a bad light because of them.

Two of the mothers in this study, both of them from Native communities, described a different perspective on disability. Disability was described as a part of life, as opposed to a negative or un-desired part of life. The following quote illustrates the collectivist and holistic thinking that can be found within many Native communities. From this particular perspective, emphasis is placed on human variability as opposed to singling out a disability. As Mary put it, “everyone has a disability in one way or another”:

> *It seems to me that the greatest difference between whites and Indians is the way that they treat those in need and their ideas of relationships. We might be poor, or even blind drunk, but somehow we take care of each other. If you have no roof over your head, you can knock on any door and somebody will take you in. They will give you their own bed or couch to sleep on. They feed you what they themselves are eating. And they won't make you feel that it's charity. It is just done automatically because there is a feeling that we are all in the same boat. There are no class distinctions. You might be only a sixth cousin but still be welcomed as a relative, part of the Tiyospaye, the extended family (Brave Bird & Erdoes, 1993, p. 137).*

Hiding parts of self and or experiences in order to save face

Five of the mothers in this study, knew at an early age that becoming a wife and mother were the two most important social roles for women within their cultural community. It was only when they became wives and mothers that they fully understood what was expected of them in order to be seen as respectable members of their cultural community. These women needed to do two things in particular in order to be respectable. The first was to carry out their roles as adequate wives and mothers as it was defined by their family and ethnocultural community. The second was to 'save face'. That is, these women were asked to maintain the proper image of their family and ethnocultural community. Therefore, they needed to hide or conceal any 'problems' that would mark their family as improper. Having a disability, or more specifically, behaving in a way that marks them out as different or reduces their ability to be a good wife and mother, marital discord, receiving attention from "the system", and their children behaving "badly" were all seen as markers of social failings and brought shame and disgrace to their families.

When many of these women were not able to "save face" they experienced the negative consequences from their family and cultural community. They experienced being called names that emphasized their 'deviance'; they were coerced into making decisions that would maintain the impression of respectability; they were excluded from important family and or cultural events; and/or, they were cast aside by their family and community altogether. Upholding family pride was also a common theme in Grewal et al.'s (2005, p. 255) study of immigrant women: "Married women experiencing marital conflict were vulnerable because of family izzat (honor and respect). It was accepted that women needed to remain in their marriages to preserve family honor and 'save face'…" Concealing their disability and or other parts of themselves that would mark themselves or their families as bad allowed them to "pass" as good wives and mothers. The concept of "passing" was coined by Goffman (1963) and described how people with disabilities went to great lengths "to pass" as "normal" in order to avoid the consequences of being labeled with a disability. Fatimilehin and Nardishaw (1994) noted in their study that Asian families pushed the marriages of women with intellectual disability in order for them to take part in a normative role with the hope of erasing their disability and allowing them to "pass" as "normal". Similarly, in Connor's (2006, p.161) intersectionality study of race, disability and gender, he speaks of Michael's story, where parts of his identity are purposefully hidden or tampered with in order for him to appear more 'normal'. In order to reduce profiling and increased risk of being targeted by the police, Michael, an 18 year black student with a learning disability cuts off his braids.

5.3.2 Lack of Resources to influence destiny

The everyday experiences of persons with intersecting identities are influenced by the 'seduction, pressure and force' of dominant culture with the intention of maintaining unequal social interactions (Collins, 2000). Within the disciplinary and hegemonic spheres, we see how oppression is rationalized and reinforced.

The life stories of these women are marked by personal struggle and a lack of power to overcome obstacles in their lives. The difficulties they encountered in escaping personal and systemic abuse is partly due to their of lack social and economic resources. All of the women in this study described abuse within their interpersonal relationships, especially with the father of their children. Many of the mothers specifically described how their husbands abused them when they were not upholding cultural expectations. For example, Harrah described how her husband 'beat me' when she did not perform adequately within the home.

The abuse experienced by these women severely impacted the way in which they saw themselves, and their sense of control or 'power over destiny'. The mothers described the abuse as debilitating and isolating and in Maria's words, 'And I couldn't move, I was still tied up. I used to yell and scream and no one would help me" (IT 1, pg.

8). Many of the women also believed (at some point in their abusive relationships) that they deserved the abuse and believed the negative things that were being said about them in being “worthless” and “good for nothing”. Dung described how her family viewed her as a ‘bad girl’ because of being perceived as ‘dumb’, and as a result, she views herself as a ‘bad girl’ within this part of her narrative. McDonald et al., (2009) also describe how some of the participants in their study internalized oppression, accepting their ‘less than’ social position, as they felt that they could not influence the way that people thought of them.

Many of the women’s families knew of the abuse that they and their children were experiencing but either ignored it, minimized it, told the woman to accept it, and/or asked them to hide it in order to protect the family’s image. The women did not feel like they could turn to their families for support during these difficult times. They did not feel as though they were heard nor did they feel like they were protected by their families. “… He beat me and I stayed at my mom’s place and they heard me screaming from the downstairs, but no one came. Not my mother. Not my father, sister, not my brother in law. Nobody came downstairs. To break down the door” (Maria, IT 1, pg.7). Many of the women had turned to the authorities (e.g., police, welfare) in order to take them and their children in. This was difficult for these women as many of them had negative experiences with “the system” and did not feel that they could trust the authorities, or that they could help them.

The barriers that are imposed upon these women, because of their intersecting social identities, pose ‘very real forms of social restraint’ (Connor, 2006, p. 159). Perhaps one of the most vivid descriptions of domination within the stories of these eight women was the rape described by Maria. This part of Maria’s life story seems to mirror some of the systemic violence that women with intellectual disability often face in society (Rohrer, 2005). The violent words that were used by her ex-boyfriend can be seen as the structural sphere promoting domination and the physical violence in itself can be seen as the acts that dominate women with intellectual disability in order to maintain oppression. This was clearly articulated by Rohrer (2005, pg. 51):

"My father raped me for many reasons, and inside his acts of violence I learned about what it means to be female, to be a child, to live in a particular body, and those lessons served the larger power structure and hierarchy as well".

Living in poverty also constrained these women's lives and minimized their ability to exercise control over their lives. All of the women in this study (except for one mother) live in poverty; most of them were on social assistance at the time of the study. This is consistent with many studies within the field, where poverty is identified as a major risk factor in the lives of these families (Aunos, Goupil & Feldman, 2004). Cheyenne, Halina and Harrah, in particular, described the struggles they encountered in meeting their family's most basic needs and the accompanying feelings of powerlessness and stress. Poverty has also been linked to increased levels of parenting stress of parents with intellectual disability (Aunos, Goupil & Feldman, 2004).

Though many of the mothers in this study discussed the ways in which they were impacted by poverty, for example, being worried about not being able to pay the bills or not having enough food, Cheyenne was the only mother that explicitly named poverty as a constraint. This was also the case in Nind's (2008) secondary analysis of family narratives on the intersections of learning disabilities and social class, where the families did not identify poverty or social class. However, Nind agrees with Reay's (1997) observation that, "Even when class is not overt and articulated in people's decoding of the social world, it is still there as a part of the implicit, taken-for-granted understandings they bring to their relationships with others" (p.227). Though the families in Nind's (2008) study, and most of the mothers in this study, didn't name poverty as a social constraint, their stories did tell the tale of inequality, specifically as they recounted a lack of resources to meet their family's most basic needs. Perhaps, "being poor" and living in poverty was so embedded within these women's lives, sometimes for generations, that it was difficult for them to see, or see that it could or should be any other way.

5.3.3 Resisting and fighting against negative messages and actions

The everyday experiences described in these women's narratives were filled with both ups and downs. Even when these women were 'down', they exercised agency in different ways by speaking up, by questioning oppressive practices, and by taking action. Collins (1990) specifically speaks to understanding and accepting different parts of "self" that is based on one's experience as opposed to the internalization of society's negative interpretation.

Rejecting negative actions and versions of self was elaborated within Maria's narrative. This was evident when she vividly described the rape by her first boyfriend. She described that even in the darkest of times, when she 'feared for my life' that she rejects the derogatory terms he used to define her as a 'bitch' and a 'whore', and tells him that she is not that way. She rejects the label that he imposes on her and resists his definition of her. Later on in her narrative, Maria describes how her boyfriend tells her parents 'he had his fun with her' after he had raped and impregnated her. In reflecting upon those words that he used to describe the rape, Maria became aware how her body becomes the center of subordination.

For me it was like damn it, asshole, {excuse my language}, but he just wanted to use me for my body. Not interested in making a life with me, just to have me as a prostitute (IT 1, pg. 7).

Maria's response shows her rejection of being used for her body or as a 'prostitute' enabling her to secure her identity and confirm what she is not. "The refusal of the mind/body dichotomy is seen as the starting point to call for the body-and-mind as a sociopolitical issue and as a subject to their analysis of power relationships" (Roets et al., 2008, p. 103). In rejecting the classification of herself solely as a body, she eliminates oppressive internalization (Collins, 2000). We see how Maria is not a passive recipient of sexual objectification, as she wants to be seen as a woman, 'who you can make a life with'.

All of the mothers in this study confronted negative views of themselves and unequal power relations in one way or another. For three of the mothers, who remain in their marriages, they questioned some of the unequal power relations within their marriage. For Harrah, who on one hand believes that a woman's role is within the home, begins to question this tradition when she is also working outside the home and bargains with her husband to help out. This was also a theme that was evident in Grewal, Bottorff and Hiton's (2005, p. 252) study as the Indian women revealed the tensions between cultural tradition and having a lack of resources in a new country, which forced many of them to join the workforce. One woman in the study states, “You find everything is different (in Canada)…. You have to look after the kids, you have to go outside and work and you have to work alongside men. Or even more, because men they’ll work 8 hours, and then they will come home and they don’t do anything else.”

Another way in which these women negotiated alternative identities, was by constructing an identity based on their own definitions as opposed to conforming to cultural expectations. Halina, Cheyenne and Sheira, in particular, used different words to described themselves, such as ‘sometimes I am disability and sometimes I am not’ or being ‘a slow learner’. The process of rejecting a devalued view of self and providing another definition is also captured in Young’s (1990) idea of ‘double consciousness’. This concept plays out within the women’s narratives as they are aware of the negative stereotypes of themselves that are out there and provide a version of themselves that tells people what they can do. Collins (1990, p.231) describes this process as it “involves rejecting the dimensions of knowledge, whether personal, cultural, or institutional, that perpetuate objectification and dehumanization”. By rejecting some of the devaluing assumptions that have been imposed on them, these women are resisting false views of themselves and their families.

Some of the mothers even described having a disability as an asset, especially when they had a child with a disability. Halina describes how her social location, as a woman/mother with intellectual disability who has experienced stigma allows her to empathize with her children in a way that a mother who has not experienced this stigma would not be able to do. Being a ‘slow learner’ could be viewed as an asset, enabling understanding of ‘what their life is all about’. Notably, Malacrida (2009) found that over one quarter of the mothers with different disabilities in her study believed that having a disability was an advantage in raising a child with a disability. This is reflected in the following “For Leanna (a mother within her study), ‘mother knows best’ a central aspect of ideal mothering, could just have readily be expressed as ‘disability knows best’ ” (Malacrida, 2009, p.108).

Perhaps, the most important way of reclaiming themselves was within their role as a mother. These women’s life stories illustrate how important their children are to them, how being a mother gives them meaning, fulfillment and a reason for being in this world. Harrah voiced the thoughts of all the mothers in this study when she said 'I am nothing without my children'. Becoming and being a mother marks a personal achievement, a valued status within their cultural community and within society as a whole. Being and becoming a mother does not come with the same negative baggage that other parts of their identity bring. Malacrida's (2009, p.114) study confirmed "… Several women in the group directly acknowledged that being pregnant and engaging in motherhood had been empowering precisely because, for the first time in their lives, they were seen as fully functioning adult women".

In claiming their mothering identity as central to who they are, perhaps these women are providing a 'resistance identity', insisting that their sense of self does not coincide with culturally given role identities. Barron (2002, p. 77) further articulates "Opposing an ascribed identity with a devalued status and attempt to (re) construct one's self-identity thus redefines one's position in society, or put differently, serves to construct a meaningful interpretation of self". As these women have reconstructed their identities within their narratives, they also provide their children with an opportunity, to re-write their own stories and to shape their own destiny.

5.4 Summary

Applying Intersectionality theory to the life stories of mothers with intellectual disability from ethnocultural communities has uncovered how oppression and resistance interact within the intersecting domains of the matrix of domination. We see how these women were sent negative messages in regards to their interrelated social identities. Essentially, these women were told that they were not good enough as they did not measure up to expectations. Once they were seen as not meeting the socio-cultural expectations that were set out for them they experienced unjust treatment. At different points in their lives they were knocked down by the oppression, yet at times they were able to exercise agency. Driving their ability to resist oppression in their lives was their desire and fight to be and be seen as mothers.

CHAPTER 6. CONCLUDING THOUGHTS

Research in the field of parents and parenting with intellectual disability has made significant contributions over the past five decades, shedding light on why some parents succeed while others struggle. This research has revealed how these parents can be supported within their parenting role, and the personal and environmental factors that impact their parenting and family life (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). The extant literature also reveals the experiences of persons with intellectual disability as parents, particularly what has brought them joy (being a parent) and what has brought them heartache in their lives (stigma, discrimination and dealing with child welfare). Most of this research has excluded or failed to highlight the experiences of mothers from ethnocultural communities and has not explored the intersections of motherhood, intellectual disability and cultural identity (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disability, 2008). The aim of this study was to explore the experiences of mothers with intellectual disability from ethnocultural communities in Canada. The narratives of the women in this study revealed how they experienced oppression within their interactions with their families, ethnocultural communities and society, and how these women reflected upon and fought against oppressions in their lives.

I would like to conclude by reviewing what we can take away from the life stories of the eight mothers with intellectual disability from ethnocultural communities within this study. More specifically, how this research contributes to knowledge in the field of parents and parenting with intellectual disability, and the implications that this has for policy, research, and empowerment. Lastly, I will provide my reflections, as a student researcher.

6.1 How does this research contribute to knowledge?

This study contributes to the body of knowledge in the field of parents and parenting with intellectual disability in a number of ways. Firstly, it is one of the first studies to use intersectionality theory to investigate the life experiences of mothers with intellectual disability from ethnocultural communities. It provides understanding of experiences from a holistic, rather than a reductionist perspective, which allows us to see the interaction between social identities (mothering + intellectual disability + culture) and larger social structures (policies, systems, values and attitudes). The narratives of the women in this study go beyond the interaction of one of their social identities and their social world; for example, their experience as a person with intellectual disability. Instead it illustrates how life is experienced by eight mothers with intellectual disability from various ethnocultural communities within different contexts and times in their lives. ,

Secondly, these narratives give us an insider's view of what life is like for mothers with intellectual disability from ethnocultural communities. It allowed us to see how they were treated by different people, institutions and systems in their lives. The way in which others saw and treated them was based on ideals and expectations that were influenced by their socio-cultural contexts. Further, these women's narratives illustrated the meaning they attached to the events and people in their lives and what was closest to these women's hearts; their children.

Thirdly, this study exposes the different and often competing messages these women received from their social and cultural milieu about what it means to be a "good" and "bad" woman. They were seen as good women within three circumstances in their lives. The first was when they got married and became mothers. The second was when they cared for their children without outside support, and when their children were behaving appropriately. The third was when they took care of their household and their husbands in the way that they were expected to. When they were seen as a "good woman" they were included in their community and felt a greater sense of belonging.

When these women were caught not 'doing as they should', their storylines shifted and they were considered "bad" women. They were seen as bad women within three contexts. The first was when their intellectual disability became visible either in their behaviours or if their disability was seen as interfering with their ability to fulfill their roles as mothers and wives. The second was when they went against the grain of their family and or cultural community. This happened when they questioned their family's or cultural community's decisions and or authority, when they questioned their husband's actions and intentions, and when they talked about getting a divorce. When they were "bad women" they were not upholding cultural and familial traditions and as a consequence were often cast aside from their socio-cultural milieu.

The women's life stories also illustrated how they struggled, challenged, conformed and resisted the different authorities in their lives. The women's ability to focus on their mothering role allowed them to feel more empowered and instilled a greater sense of hope in their lives. It also seemed to provide them with a chance to break away from 'cultural scripts' by creating a mothering identity that was constructed by their own needs and desires.

Exploring these women's life stories within an intersectionality theory framework allows us to see the varying degree and amount of penalty and privilege that operated in their lives as they interacted with their family, cultural community and mainstream society.

6.2 Intersecting oppressions and strategies for change

The women in this study faced multiple and intersecting oppressions at different levels within the matrix of domination (Collins 1990, 2000). Within the structural level, we see how vague policies of what constitutes 'good enough parenting', within the Youth Protection Act, often places these mothers at a disadvantage as prejudicial views about their parenting abilities can creep into the child welfare decision making process. The mothers in this study were able to identify some of the stereotypes that people had of them, and how they felt they were treated unfairly within the child welfare system. International research reveals that parents with intellectual disability are over represented within child welfare cases for alleged neglect, sometimes with little proof of child maltreatment (Booth et al., 2004; Llewellyn et al., 2003). Discrimination in policies and practices has been named as one of the most predominant causes of over-representation (Booth, 2000; McConnell, Llewellyn & Ferronato, 2000).

Analysis of oppression within the disciplinary level shows that these mothers faced workers and systems that were unable to respond to their needs (lack of resources or knowledge of intellectual disability + parenting + culture), provided support that was not helpful or even detrimental, and services that were crisis driven (rather than pro-active or preventative) which further put these families at a disadvantage.

Exploring oppression these women experienced within the hegemonic sphere illustrates the deep and pervasive social attitudes that these women faced about their intersecting social identities. Social media is a medium that reflects social attitudes and or can reinforce negative attitudes in relation to marginalized groups (Collins, 2000). There have been articles and a few movies on parents with intellectual disability within mainstream media, however, much of the social media reinforces negative stereotypes instead of showing how these parents can successfully raise their children. This reinforces the prejudices that persons with intellectual disability face as they are portrayed as incapable parents. The mothers in this study also faced unrealistic standards in regards to their interweaving social identities (woman, mother, wife and person with a disability) from their cultural community and family. They often faced humiliation and isolation when it was discovered by their family and or cultural community that they failed to meet these expectations, reinforcing their “less than” identity (Booth & Booth, 1995).

Within the interpersonal level, we see how these mothers struggled and exercised agency in their daily lives. They experienced physical, emotional and sexual abuse at the hands of important people in their social world including family members and spouses, experienced separation or loss of their children within a child welfare context, loss of an important person in their life and struggled to survive; keep their family together and make ends meet while living with little financial means. Seeing these women’s stories through an intersectionality theory lens highlights the intersecting oppressions these women faced within the four levels of the matrix of domination (structural, hegemonic, disciplinary and interpersonal). It also helps highlight actions that can be undertaken at all levels.

In order to address the multiple, pervasive and intersecting levels of oppression that mothers with intellectual disability from ethnocultural communities face, a multi-pronged strategy is necessary (Collins, 1990; Connor, 2006). Self-advocates and allies need to come together and take actions simultaneously on all levels of the matrix of domination (structural, disciplinary, hegemonic, interpersonal). Interventions need to run in parallel in order to address the underlying and intersecting roots of oppression. Addressing one level of oppression will only create surface changes and will not tackle the deep and interweaving levels of oppression that these women face. Therefore, the strategies outlined below should be considered elements of a one, holistic, systematic plan. These actions are suggested ideas that have been explored within the research and can be tested within future research studies.

Strategies for change on the structural level

Many mothers with intellectual disability from ethnocultural communities face discrimination in their role as mothers. In order to take action and create change we must acknowledge that mothers with intellectual disability from ethnocultural communities are subject to discrimination, particularly within the child welfare system. This discrimination is, in large part, attributable to unfair policies and practices that reinforce their oppression (Booth et al., 2004). It needs to be recognised by advocates, researchers, clinicians, lawyers, policy makers and families.

Once discrimination is recognised, some legal instruments can be used to advocate for the rights of these mothers (Llewellyn, 2013). The United Nations Convention on the Rights of Persons with Disabilities (CRDP), such as Article 23, Respect for Home and the Family, can be an instrument that is used to lobby for "States Parties … to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others" (CRDP; United Nations, 2006). In the province of Quebec, for example, one of the ways in which legal instruments can be used to bring about social justice is by increasing the collaboration between the "Commission des Droits de la Personne et de Droit de la Jeunesse" and Health and Social Services to address the discrimination against mothers with intellectual disability. This can lead to increased investigations within the child welfare system and enforce laws that are based on the right to receive support within parenting role, including collaboration between organizations to best meet the parent's needs (CRDP; United Nations, 2006 article 5).

Another important step would be to implement a national strategy that would aim at building systems capacity, in order to meet the needs of families headed by parents with intellectual disability, such as Health Start in Australia (McConnell, Matthews, Llewellyn, Mildon & Hindmarsh, 2008). In order to deliver evidence-based programs to families headed by persons with intellectual disability Healthy Start provides some of the resources needed in order to facilitate knowledge transfer and support leaders and frontline workers throughout the process. There are three facets to the Healthy Start initiative. The first is identifying and supporting leaders and managers within national, regional and local areas within the capacity building efforts. The second is increasing access to knowledge and innovation through training and web accessible resources (www.healthystart.net.au/). There are over 400 scientific journal abstracts and practice points that can be accessed by front line workers (mainstream or specialized, youth protection), lawyers, advocates, hospital staff, etc. A special section on oppression/discrimination and the ways in which to use research and policies to advocate for the rights and empower parents with intellectual disability can be integrated on the website. The voices of parents with intellectual disability should also be included and illustrate both the personal and systemic barriers in their lives and the ways in which they have been able to raise their children (success stories). The third facet of this initiative is to build and support peer networking where regular meeting points occur (online or in person) to exchange information and expertise, brainstorm clinical and systemic issues, and create concrete partnerships with parents and organizations in order to better support these families. Implementing Healthy start would promote partnerships between service sectors and agencies, and allow mothers with intellectual disability to benefit from current best practices.

The mothers in this study also discussed the ways in which their communities impact their daily lives. In order to build supportive communities for these families, collaborations between families and community centers and members need to take place. For example, there can be an expansion on the pilot project implemented by Batshaw Family Youth and Social Services (a Youth Protection organization in Montreal, Quebec) where families and community organizations get together to discuss needs and how they might work together. Different community organizations that could be engaged within this process could include, but are not limited to: community/collective kitchens, cultural community centers, recreational/after school programs, Big Brother and Big Sister, YMCA, daycares, libraries, adult learning centers, volunteer organizations and food banks. There is also a need to implement proactive services within the community and within schools for children and younger persons with intellectual disability (and their families) based on validated programs. This program could include sessions on decision-making and problem solving; sexuality and relationships; and, parenthood (Llewellyn, 2013). This could build knowledge, empower persons with intellectual disability, reduce the likelihood of abuse, and foster positive relationships.

Strategies for change on the hegemonic level

Within the hegemonic sphere, one of the ways of combating negative ideologies and internalizing oppression is by encouraging self-defined identity based on women's experiences rather than authoritative knowledge. This can increase self-confidence and reduce abuse and marginalization (Collins, 2000). Collins (2000) breaks this down into two steps. The first step involves "gaining critical consciousness". This can be attained by reflecting on questions such as 'how am I perceived by others?'; 'how do I see myself?'; and, 'how is this any different from the ways others might see me?'. The second step involves "creating new knowledge" of the ways things are supposed to be within their family and society, in order to "jump outside the frames and systems authorities provide and create own frame" (Collins, 2000, p.110). Through such a process a woman may construct her own definition of who she is and wants to be, instead of relying on unattainable expectations that further reinforce oppression.

In order to create opportunities to empower mothers with intellectual disability from different ethnocultural communities in the way Collins (2000) describes, a national project based on the principles of the 'Supported Learning Project' (Booth & Booth, 2003) could be implemented in every province in Canada. This program has implications for the hegemonic and interpersonal spheres of the matrix of domination as the objectives are centered on empowering parents with intellectual disability and creating change at the systemic level. The program is based on self-advocacy principles where the mothers are engaged in a self-advocacy process within a group setting. Booth and Booth (2003, p.182) define self-advocacy as "People working together to find their own voice, speak up for themselves, recognize their strengths, make their own decisions and, in the case of project mothers, identify their own learning needs as parents". Within the SLP project, this includes 1) Awareness: identifying oppression, rights and strengths; 2) Self-help: identifying ways in which strengths could be used to take action; and, 3) Mutual action: uniting together in order to press for social change. Mothers within the mutual action phase of the program can create a “project” which can include a video of positive experiences, a book of narratives, an ethno drama, and/or any other creative production. The emphasis is placed on positive experiences and strategies of resistance. These projects can also be implemented in collaboration with university programs such as social work, law and journalism/communication (film). This could facilitate the process and increase awareness of these mothers’ perspectives, and can identify the systemic barriers these mothers face. The finished project could be presented at a community center, where families and community members would be invited to participate, and coalitions of persons and groups that are committed to social justice initiatives can be built. Partnerships can be built between mothers with intellectual disability from ethnocultural communities, independent living organizations and DAWN (a feminist organization for women with disabilities that utilises intersectionality theory) in order to empower self-advocates and build alliances.

Strategies for Change on the interpersonal level

Establishing platforms for empowerment with mothers with intellectual disability at the interpersonal level is vital in order to stimulate change. For mothers who are uncomfortable or not ready for a group setting (that is proposed within the supportive learning program), these mothers might be encouraged, on individual basis (within a therapeutic setting) to write, co-write or narrate their life story. Engaging in this process could enhance their voice; enabling these women to identify their needs, the barriers they have faced in their life including the abuse they encountered and the ways in which they have exercised agency. These narratives can be used within clinical practice or within a community setting instead of relying solely on clinical assessment tools (Davies, 2005).

Support groups could also be created and implemented in order to meet the psychosocial needs of mothers with intellectual disabilities from different ethnocultural communities. Support groups around issues of abuse could explore the patterns of abuse, identifying positive and negative relationships, personal objectives they have for themselves and their families and tools and resources that could further support these mothers. Further, for parents who have a child in placement support groups like "parents on the outside" that offer mutual peer support, sharing and normalizing of experiences, information and resources for mothers with intellectual disability that have experienced a loss of a child through child welfare placement can also be implemented (Mayes, Tozer and Elder, 2011).

Another important component of a holistic, systematic plan would be to equip frontline social workers with the knowledge and skills they need to effectively support parents with intellectual disability (including awareness or sensitivity of the influence of culture on parenting practices, traditions etc.). This could be achieved, at least in part, by creating a unit of study on parents and parenting with intellectual disability and integrating this into social work programs across the country (McConnell, 2013). Social work students would have the opportunity to learn about best practices in this field, including assessment and intervention practices. Further, this curriculum could include a self-reflection component: Davies (2008, p.149) suggests that social workers, and child welfare workers in particular, "Require the space and permission to reflect, process and contain their reactions to their clients." The curriculum might include the following:

1) History of oppression
2) Context (policies, rights)
3) Theoretical orientations and approaches
4) Assessment practices
5) Parenting education and family support
6) Self-reflection (influence of values/bias on assessment and intervention)
7) Parents voices/experiences, strengths and resilience
8) Advocacy and empowerment

6.3 Recommendations for Future Research

This research study has shed light on the experiences of eight mothers with intellectual disability from ethnocultural communities and has explored the connections between the micro and macro aspects of human existence (Connor, 2006). This study makes several contributions, however, it has also revealed some areas that deserve increased attention within future research studies.

The mothers in this study expressed how they felt their culture and family empowered them in some instances and disempowered them in other instances. A way in which to gain understanding of how families and culture can empower and or positively impact the lives mothers with intellectual disability from different ethnocultural communities would be to conduct an interpretive study. This study could investigate the way in which support is seen and given from informal networks within the lives of families from various ethnocultural communities. The narratives of these families could also be explored in order to include the perspectives of all family members, including extended family members. Furthermore, a future study could explore the way in which disability is viewed in different cultural contexts, including Native communities and how perceptions of disability can influence how support is offered by families and perceived by mothers with intellectual disability and how this might impact these women's experiences.

Another study could investigate the way in which culture influences the everyday parenting practices of mothers with intellectual disabilities. This research could also identify the support needs of mothers with intellectual disability from various ethnocultural communities and ensure that best practices within parenting training programs are culturally appropriate.

All of the mothers in this study disclosed abuse either within their family of origin or within their relationships with their significant others. The research shows that violence against women with disabilities, especially women with intellectual disability, is widespread and long standing (Thomas, 2002; Rohrer 2002). There have been some studies that have explored abuse or upbringing in the lives of these families as a part of a larger research study (Booth & Booth 1994, 1998; Llewellyn & McConnell, 2010) but there have been few studies that have focused on the abuse that mothers with intellectual disability often encounter in their daily lives. There is a need for future studies to explore the experience of abuse from these women's vantage point within a cross-cultural perspective. For example, how abuse impacts the life stories, relationships, identity, self-esteem and mothering of women with intellectual disability from ethnocultural communities. Further, the ways in which these women dealt with the abuse in face of great adversity, should be explored along with the way in which the larger socio-cultural context responded to the abuse. This study could provide increased understanding of the abuse that mothers with intellectual disability from different ethnocultural communities face, and what strategies of change could be explored in order to create social change in the lives of these women.

Poverty was another social location that was described, on some level, by the mothers in this study, however, it was not explicitly and elaborately expressed. I contend, with Nind (2008, pg.97), that "(l)earning difficulties and other disabilities may become evident whatever one's socio-economic status or class position, but what happens next is a different story". Social class can be an invisible force that reeks havoc on the lives of individuals and their families, but the impact is visible and needs to be further explored within research studies. We need to understand, why is poverty a taken for granted position? Why might it be difficult for mothers with intellectual disability to identify poverty as a barrier? What are some of the ways in which mothers with intellectual disability use strategies of resistance in face of poverty? This is especially important as many studies have illustrated that most parents with intellectual disability live below the poverty line and that poverty is seen as the largest risk factor in their lives (Aunos, Goupil & Feldman, 2008; Booth & Booth 1995, 1998; IASSID, 2008; Llewellyn & McConnell, 2005). Social class should be included in future studies that aim at further understanding the social positions that people occupy and the mechanisms that are at play that help reinforce "less than" positions in society.

6.4 Considerations

This study used a narrative approach to investigate the experiences of eight mothers with intellectual disability from ethnocultural communities in Canada. As with most narrative studies, the sample size was small. The findings are not therefore generalisable in the numeric sense. *An entirely different research design, including a different sampling frame and recruitment strategy, would be required if the purpose of the study was, for example, to determine the level of exposure of mothers with intellectual disability from ethnocultural communities to partner violence.* However, numeric generalisability (i.e., the capacity to infer something about a population from a sample) is not the objective of narrative research. Rather, the objective is to generate insight into the lives of research participants and the meanings they attach to, or 'make out' of their experiences. To achieve this, the narrative researcher requires 'thick' and 'rich' data.

Notwithstanding, narrative research does not simply provide ‘evidence’ or insight into the lives of individual research participants The narratives of individuals provide a means of understanding more about the broader culture shared by a community of individuals (Chase, 2005). Chase (2005, p. 20), for example, argues that “(l)ife stories themselves embody what we need to study: the relationship between this instantiation (this particular life story) and the social world the narrator shares with others; the ways in which culture marks, shapes and/or constrains this narrative; and the ways in which this narrator makes use of cultural resources and struggles within cultural constraints”. Citing Sheherazade’s dictum (from Arabian nights), Booth and Booth (1998, pg.58) get at the same point, only in fewer words, “(o)ne life is simply all lives lived separately”. This explains why common themes or storylines can be, and were found across the individual narratives of the eight women who took part in this study: these narrators come from similar social positions in society and experience oppression because of their marginalized status.

Another consideration is that the mothers in this study were recruited from clinical samples. It is possible that the mothers’ experiences might differ had they been recruited from a non-clinical sample, in other words, mothers who do not receive specialized services. It could be very interesting to conduct another study with mothers with intellectual disability from ethnocultural communities who do not receive specialized services in order to further understand their experiences. It might reveal a different point of view with regards to their interactions with family and their community. However, this type of study may pose certain recruitment issues as these mothers represent a small sub-group of an already small group within the population and would therefore be difficult to locate.

6.5 Reflections

Reflection was an important part of my research process. I reflected upon my role and my social position and how this impacted different parts of the research process. I reflected upon what I heard the mothers saying and what it could mean. I reflected upon what bound these mother’s stories together, in order to further understand the dynamic interaction between interrelated social identities and the different socio-cultural contexts in their lives. I reflected upon what I heard and interpreted and how this could contribute. I reflected upon the feedback and questions that I received from my PhD supervisor, my supervisory committee, fellow PhD students and researchers in order to delve deeper into the heart of these women's life stories.

As part of this research explores the power relations between these women and social forces in their lives, it only seems appropriate to consider and explore the hierarchal relationship between myself (as the researcher) and the mothers (the participants/narrators). I used a collaborative approach in my study, in many ways. First, I began the process by asking each woman where she wanted to begin, instead of using structured questions. I invited the mothers to tell me their story, at their own pace and within their own chosen space. Second, I tried to facilitate a dialogue, where the women were free to ask me any questions about myself and the research process. Third, when putting together the narratives, I tried to keep as much of the women's voice and quotes as possible. Fourth, I presented each of the mothers with their narratives and asked them to verify and adjust in order to 'stay true' to their story. Fifth, since the beginning of the process, I have tried to make clear that the narratives of these women are not solely a product of their mind, but a 'creation of our two minds working together' (Booth & Booth, 1998, p.138).

Though I did consider ways to establish collaboration with these mothers, I am conscious of my position. My position as a white middle class woman, from an ethnocultural community with an impairment/disability, a PhD student researcher and the privileges that come along with this social identity. I am conscious of my agenda, in part to hear and disseminate the stories of mothers with intellectual disability from ethnocultural communities in order to provide a counter narrative, the other part to fulfill the requirements of my PhD studies. I was conscious of my position throughout, and used my reflective log to jot down some of my thoughts and reflections.

Hearing, documenting and co-constructing these women's life stories was where I spent the most time and energy as a doctoral student. Their story has now become our story. I want to end by sharing a poem that I wrote about my reflections and participation in these women's lives.

The Voice of Mothers

You have let me into your lives, your hearts and your homes.
You have shared with me your most personal stories.
Some of you for the first time in your lives.
You have told me about your deepest fears
and the most memorable moments in your life.
You have told me about your families, your country and your community.
You have told me how you often felt judged and not good enough as women and mothers.
You have shared with me the most important day of your lives, the day that you brought your children into this world.
You have told me about what is like to be a wife. A mother. A daughter. A sister.
You have told me how you will stop at nothing to have your children in your lives, to have, to love and to hold.
You have told me what has hurt you the most;
being blamed, devalued and shamed for who you are and what has happened in your life.
By your family, your cultural community and society.
You have told me about the abuse, the discrimination and how you struggled to provide for your children.
I have heard and listened to your stories.
Over and over again.
I am honored that you have shared your stories with me.
Privileged to have heard them
and humbled by them.
Your story has now become a part of my story.
I hold your stories very dear and take responsibility,
so that the world can see;
That you are women,
That you have a voice.
Who are fighters.
And most of all you are mothers.

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Appendix A

Consent form (copy for participant)
Title of project: Mothers with intellectual disability from ethnocultural communities

Student researcher: Ms Laura Pacheco phone: 514 363 3025 ext. 2258
Student supervisor: Dr David McConnell phone: 780 937 4101

	Yes	No
Do you understand that you have been asked to participate in a research study?	☐	☐
Have you received and read a copy of the attached information sheet?	☐	☐
Do you understand that participation is voluntary?	☐	☐
Do you understand that you are free to withdraw at any time, without having to give a reason and without affecting your future services?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your information?	☐	☐
Do you understand that you can contact the researchers at any time if you have any questions or concerns?	☐	☐

I agree to take part in this study: YES ☐ NO ☐

Signature of research participant: ______________________________

(Printed name) ______________________________
Date: ______________________________

Signature of witness:……………………………………………………………………

I believe that the person signing this form understands what is involved in this study and voluntarily agrees to participate.

Signature of researcher: DBMcConnell Date ____________________

Dr. David McConnell

Appendix B

Consent form (copy for participant)
Title of project: Mothers with intellectual disability from ethnocultural communities

Student researcher: Ms Laura Pacheco phone: 514 363 3025 ext. 2258
Student supervisor: Dr David McConnell phone: 780 937 4101

	Yes	No
Do you understand that you have been asked to participate in a research study?	☐	☐
Have you received and read a copy of the attached information sheet?	☐	☐
Do you understand that participation is voluntary?	☐	☐
Do you understand that you are free to withdraw at any time, without having to give a reason and without affecting your future services?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your information?	☐	☐
Do you understand that you can contact the researchers at any time if you have any questions or concerns?	☐	☐

I agree to take part in this study: YES ☐ NO ☐

Signature of research participant: ______________________________

(Printed name) ______________________________
Date: ______________________________

Signature of witness: ……………………………………………………………………
I believe that the person signing this form understands what is involved in this study and voluntarily agrees to participate.

Signature of researcher: DB McConnell Date ________________
Dr. David McConnell