

**My mother, my daughter, my self:  
The mother-daughter relationship & the influence of facial differences**

**by  
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## **ABSTRACT**

### **MY MOTHER, MY DAUGHTER, MY SELF: THE MOTHER-DAUGHTER RELATIONSHIP & THE INFLUENCE OF FACIAL DIFFERENCE**

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While research on facial differences has burgeoned in recent decades, critical scholars note that the existing literature overemphasizes the negative impacts of living with a difference, and limits the discussion of individuals' relationships. This paper reports on a qualitative study that explored the mother-daughter relationship when the daughter is living with a facial difference. Ten young women, age 13-22 with facial differences, and their mothers were interviewed. Mothers assumed a number of roles in their daughters' lives, and communicated empowering messages to their daughters, so to afford them emotional armour in the face of marginalization. Mothers and daughters also demonstrated "exquisite attunement" in their relationship, respecting each other as interconnected beings and vital sources of learning and support. This model of the mother-daughter relationship not only serves to enrich the existing literature on facial differences, but presents alternative ways of conceptualizing and supporting individuals and families touched by facial difference.

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## Introduction

Facial difference is the generic term used to denote a variety of conditions that affect the structures of the head and face. These include congenital conditions that are present at birth (cleft lip and palate, cranial and facial conditions, birthmarks, and port wine stains); acquired conditions that develop across the lifespan through accident, illness, and surgery; and so-called “orphan conditions”, or facial differences that are diagnosed in less than 1 in 200,000 individuals (Charkins, 1996). Each year in Canada, approximately 17,000 babies are born with a facial difference, which translates into 4% of the Canadian population or more than 1.5 million individuals coast to coast (AboutFace, 2010). Rates of acquired facial differences are difficult to report due to variation in age and types of conditions among people who develop them, but based on Eiserman’s (1986) unpublished data, the annual number of cases exceeds 280,000 in the United States.

The impact of facial difference on the lives of individuals is a topic studied widely within the discipline of psychology over the last fifty years (Beaune, Forrest, & Keith, 2004; Bilboul, Pope & Snyder, 2006; Broder & Strauss, 1991; Bull, 1990; Bull & Rumsey, 1988; Chibbaro, 1999; Kapp, 1979; Lefebvre & Arndt, 1988; Lefebvre & Munro, 1978; Pope, 1999; Richman & Eliason, 1982; Rumsey & Bull, 1986; Speltz Galbreath, & Greenberg, 1995; Turner, Rumsey & Sandy, 1998). Among the most commonly cited issues are self-doubt, low self-esteem, poor self-confidence, unfavourable body image, and negative self-images among children and youth with facial differences (Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997; Millard & Richman, 2001; Rumsey & Harcourt, 2004; Turner, Thomas, Dowell, Rumsey, & Sandy, 1997). Previous research also suggests that individuals with facial difference are subject to psychosocial difficulties at “higher-than-expected rates” (Maris, Endriga, Speltz, Jones, & DeKlyen, 2000) including: internalizing and externalizing disorders (Pope & Snyder, 2005; Speltz, Morton,

Goodell, & Clarren, 1993); negative self-evaluations (Kapp-Simon, 1986; Broder & Strauss, 1989); difficulties with peers (Kapp-Simon & McGuire, 1997); and learning problems (Broder, Richman, & Matheson, 1998; Richman, 1980; Richman, Eliason, & Lindgren, 1988; Tobiasen & Speltz, 1996).

There are however, a number of issues with the ways in which psychology scholars operating outside a critical, feminist framework have historically conducted research in the area of disability and specifically, facial difference. As critical psychologists' Dan Goodley and Rebecca Lawthom (2006) argue, much of conventional psychology's exploration of disability and difference should be "distrusted" because its approach has tended to be acontextual and normalizing, and it's theorizing, oppressive in so far as it has contributed to the framing of individuals who embodied difference or disability as "deficient". As a discipline, it has been primarily concerned with understanding how individuals "adjust" to their impairment, and has maintained that when maladjustment occurs, the appropriate response is to change the person rather than their social networks or the society in which they are situated.

This problematic focus on the individual as deficient relative to the normative subject to which the disabled other is implicitly compared is particularly evident in the literature on facial difference. For instance, most of the research focuses mainly on how facial difference complicates, troubles, or reduces an individual's quality of life (Broder & Strauss, 1991; Endriga & Kapp-Simon, 1999; Lansdown, 1981; Lefebvre & Munro, 1978; Maris et al., 2000; Richman & Eliason, 1982; Rumsey & Bull, 1986; Speltz, Arnsden, & Clarren, 1990; Speltz, Greenberg, Endriga, & Galbreath, 1994; Turner et al., 1998). The majority of studies are quantitative in nature and focus on producing reliable and generalizable findings, which results in a significant oversimplification or omission of the complex subjective experiences and relationships of

individuals touched by a facial difference (Broder & Strauss, 1991; Bilboul, Pope, & Snyder, 2006; Pope & Snyder, 2005; Richman & Harper, 1978; Snyder, Bilboul, & Pope, 2005; Speltz et al., 1990; Topolski, Edwards & Patrick, 2005). To date, very few studies make use of qualitative methods or consider alternatives to the negative framing of disability (Beaune et al., 2004; Eiserman, 2001; Locker, Jokovic, Stephens, Kenny, Tompson, & Guyatt, 2002; Klein, Pope, Getahun & Thompson, 2006; 2010; Tanner, Dechert, & Friedern, 1998). Most importantly however, there exists very little literature that explores the type and quality of relationships that individuals living with a facial difference look to create and experience, especially beyond their first few years of life.

### **Objectives of the “My Mother, My Daughter, My Self” Project**

The current study looks to fill in some of the gaps in the existing psychological literature on facial difference, and adopts a critical feminist disability framework to present an alternative means of understanding relationships in the context of facial difference. Specifically, the project aims to qualitatively explore the mother-daughter relationship when the daughter is living with a facial difference, a topic that remains previously unaddressed. The specific objectives of the project entail: a) exploring mothers’ role in their daughters’ navigation of social interactions, family adjustment, and encounters with the medical system; b) examining the ways in which mothers help their daughters transition through adolescence, and develop a sense of self, body and gender; c) understanding what facial differences can uniquely contribute to a girl’s sense of self and the mother-daughter relationship; and d) analyzing the way in which a woman might mother differently when she too is living with a facial difference.

The project sought to answer four specific research questions that parallel its objectives: a) what role do mothers play in helping their daughters navigate through the various experiences

that are common in the lives of individuals with facial differences, including family adjustment, social interaction, and medicalization?; b) in what ways do mothers influence their daughters' development of a sense of self, body and gender in adolescence?; c) how has a daughter's facial difference contributed to her sense of self and her relationship with her mother?; and d) is there a difference in the experiences of the mother-daughter relationship when the mother is also living with a facial difference?

### **The Use of the Term “Difference”**

The terminologies used to date in empirical literature to refer to facial difference, including words such as “disfigurement”, “anomaly”, “abnormality”, “deformity”, and “defect”, have predominantly negative denotations and connotations and are consistent with the medical model of disability (Bilboul et al., 2006; Bradbury & Hewison, 1994; Campis, DeMaso, & Twente, 1995; Klein et al., 2006; Pope & Snyder, 2005; Pruzinsky, 1992; Snyder et al., 2005; van Staden & Gerhardt, 1995). This theoretical framework is inherently problem-focused, and posits that difference is pathological (Rumsey & Harcourt, 2004). According to Eiserman (2001), this terminology serves to exacerbate the challenges that individuals encounter in a society rejecting of difference by further alienating them. Instead of such stigmatizing language, the preferred term among communities of people living with difference is “facial difference”, as it implies a naturally occurring phenomenon; no two people look alike (Rumsey & Harcourt, 2004). As such, the term “difference” will be used in the within the present study.

### **Literature Review**

Children and youth take in the cultural meanings that are assigned to bodies, and gather others' perceptions of how they look and who they are (Rice, Renooy, Zitzelberger, & Aubin, 2003). Families, peers, and medical settings all contribute to the way in which a child's bodily

awareness is developed; the judgements these external sources pass on a child's body and appearance interact with a child's views of themselves to create an overall self-image, which can be positive, negative, or both (Jenkins, 1996). A substantial portion of previous literature in the area of facial difference focuses on the way in which family dynamics, social interactions and involvement within the medical system contribute significantly to individuals' self-perceptions (Bilboul et al., 2006; Bradbury, 1993; Bradbury & Hewison, 1994; Broder & Richman, 1987; Broder, Smith & Strauss, 1992; Endriga & Kapp-Simon, 1999; Lansdown, 1981; Lefebvre & Munro, 1978; Macgregor, 1979, 1990; Maris et al., 2000; Pope, 1999; Pruzinsky, 1992, 2002; Reischer & Koo, 2004; Renooy, Rice & Beveridge, 1999; Rice, 2014; Robinson, 1997; Rumsey & Harcourt, 2004; Slutsky, 1969; Snyder et al., 2005; Speltz et al., 1994, 1995; Topolski et al., 2005; Turner et al., 1998; van Staden & Gerhardt, 1995; Walters, 1997; Wasserman, Allen, & Solomon, 1986) and together, experiences in these three domains are the main focus of my literature review, given that they serve as the key systems that mothers help their daughters' navigate. Firstly however, the rationale for choosing mothers and daughters as the primary persons of interest will be examined. Findings from within the existing psychological literature will then be presented, along with a discussion of how familial, social, and medical experiences are said to specifically impact an individual's sense of self. A demonstration of research from other disciplines and theoretical frameworks will follow to critique the dominant discourses of disability and difference, and present an alternative literature in the area.

### **Why Study Mothers?**

The decision to study mothers exclusively was an important one, given that they occupy an interesting position in developmental literature, both historically and more recently, particularly in their relationships with their daughters. According to Smith, Mullis and Hill

(1995), the mother-daughter relationship is regarded in psychology as one that is extremely complex, yet critical across the lifespan. Hirsch (1981) describes it as “the most formative relationship in the life of every woman” (p. 200). Through the processes of observation and modelling, mothers serve as the initial source of sex role learning for their daughters, and daughters come to recognize that they share a large commonality with their mothers through gender (Litton-Fox, 1980). As such, mothers are considered the most significant female role model for their daughters (Usmiani & Daniluk, 1997). Because daughters admire and identify so strongly with their mothers, they strive to be like them and adopt their attitudes, behaviours and values (Ogle & Damhorst, 2003). Similarly, mothers identify with their daughters because they share a gender, and may behave towards their daughters the way they act towards themselves (Eichenbaum & Orbach, 1983). Altogether, these processes have previously been thought to blur the boundaries within the individuals in the dyad, and leave daughters struggling to separate from their mothers for their entire lives, causing the conflict and tension that has been said to plague the mother-daughter relationship throughout history (Boyd, 1989; Chodorow, 1974; Fischer, 1986; Friday, 1977; Pipher, 1994; Smith, et al., 1995; Usmiani & Daniluk, 1997).

There are a number of inherent flaws within this historical view of mothers’ role in child development however. Historically, separation and differentiation were thought to be a normal, fundamental goal in the development of all individuals (Conarton & Silverman, 1988), and for women specifically, the effort to become autonomous from one’s mother was considered a life-long, critical process (Baruch & Barnett, 1983; Chodorow, 1974). Many girls and women are told that the problems that arise in the relationships with their mothers occur because they are “too connected”, and that the only solution is to emotionally distance themselves (Caplan, 2000). However, in recent years, developmental psychology has emphasized the simultaneous process of developing an autonomous, independent sense of self in the context of close relationships

(Cleveland & Reese, 2005; Grotevant & Cooper, 1985; Grotevant & Cooper, 1998; McLean, Breen, & Fournier, 2010). In fact, the psychological strength of girls in particular is said to derive from their connections with significant others (Brown & Gilligan, 1992; Debold, Wilson & Malave, 1994; Gilligan, 1991; Ward, 1996).

The current feminist developmental conceptions of the mother-daughter relationship reconceptualise it as critical to female development across the lifespan, rather than in just the first few years of life (O'Reilly, 1998). According to Debold, Wilson and Malave (1994), mothers are pressured to disconnect from their daughters in order to be praised for “mothering right”, however, rather than strengthening girls, this abandonment renders them “weakened and adrift” in a time when they are most in need of stability and trust (p. 36). The stress and pressure that girls experience in adolescence can be conceptualized as “a loss of control in many areas of their lives, a struggle to create an identity and a belief system to which they can wholeheartedly commit, and a sense of isolation within the challenges that face them” (Debold, Brown, Weseen, & Brookins, 1999, p. 190). Thus, girls need to be encouraged to forge strong bonds with adult women, namely their mothers and “other-mothers” (i.e. women in extended family, friends, teachers and counselors), rather than move away from them. These relationships can facilitate “hardiness” in young girls, and help them develop the ability to resist these stresses, and connect to their own sense of self-worth (Debold et al., 1999). Moreover, relationships with their mothers may serve as strength, guidance, and protection for young girls as they navigate their adolescence (Apter, 1990; Brown & Gilligan, 1992; Debold et al., 1994; Lowinsky, 1992; Orenstein, 1994; Pipher, 1994; Rutter, 1996; Ward, 1996). As Rutter claims (1996):

The mother daughter relationship is the ground for teaching, taking, and sharing the feminine experience and the more we empower that experience, the healthier our girls will be. We need to secure our daughters' sense of self-worth, in their

mind and their bodies, so that they will not turn away from us and from themselves. (p. 9-10)

Therefore, the view of the mother-daughter relationship adopted within the project *My Mother, My Daughter, My Self*, was consistent with these more recent feminist developmental conceptualizations of the mother daughter relationships. Rather than emphasizing the necessary separation to develop an autonomous sense of self, it ascertains that the mother-daughter connection is vital to empowering adolescent women, and celebrates the relationship as a “site of female renewal and feminine resistance” (O’Reilly, 1998, p. 17).

**Mothers in disability literature.** The role of mothers becomes increasingly complex and vital when raising a child with a physical difference or disability. In her study of the dynamics of caring for children with disabilities, Traustadottir (1991) found that care work is gendered (considered a woman’s responsibility) and multifaceted. Women in her study identify three different meanings of caring: “caring for” or taking care of the child, the hard and sometimes demanding work that can require specialized knowledge; “caring about” which includes loving the child; and the “extended caring role” in which mothers extend their care beyond their own children into the broader community of children with disabilities. Attitudes about the caregiving role also vary among mothers. Some view the caring role as an empowering experience, while others view it as a disruption, or simply “part of one’s life”. Fathers are not found to occupy similar roles in caregiving for their child. Instead, they are seen by families as “helping out”; providing support to mothers when making decisions regarding their child’s care, and providing the necessary financial support to allow for the best possible care (Traustadottir, 1991).

Due to the gendered ideology of care, the responsibility for children with a disability largely falls on mothers’ shoulders. Mothers tend to support their children through educational and medical systems (Rice, 2014), and thereby confront similar barriers and stigmas that their

children encounter such as poor, inconsistent medical care, inappropriate educational placements, and insufficient child care, (Darling, 2003; Dowling & Dolan, 2001). Additionally, mothers frequently search out appropriate services for their children, and interact with the various professionals with whom the child becomes involved over their lifetime (Rice, 2014; Traustadottir, 1991). By way of their increased involvement, mothers are often the parent who seeks out information regarding their child's condition and creates a space in which their child feels protected and valued. In Rice's study (2014), mothers' loving touch and gaze was of extreme importance to individuals with disabilities and differences, acting as a "reservoir of positive body memories" that they could reference when feeling stigmatized (p. 56). As a result, mothers tend to understand their children's needs and interests in ways that others do not (McKeever & Miller, 2004).

While a substantial amount of research in disability studies frames mothers in a positive light, some literature suggests that non-disabled mothers occupy a difficult, sometimes contradictory position in the disabled community. Specifically, researchers have called into question the ability of non-disabled parents to act as role models for their children with disabilities (Middleton, 1999; Ryan & Runswick-Cole, 2008). Many mothers have very little or no experience with disability before the birth or diagnosis of a child with impairments, and therefore lack an appropriate parenting guide (Greenspan, 1998; Middleton, 1999). Consequently, the actions of some mothers have been viewed as constraining and oppressive, and interpreted as attempts to normalize their child rather than value their difference (Ryan & Runswick-Cole, 2008; Veck, 2000). Moreover, although raising a child with a difference or disability is often an unexpected, undesired, and "fundamentally different" occurrence for many non-disabled mothers, there is little room for mothers to honestly articulate their experiences

without confirming what the dominant societal discourses imply about disability; that it is unbearable, and reduces one's quality of life (Greenspan, 1998).

Mothers were included within the study because of the distinct position they occupy in the lives of children with disabilities. By investigating the role a mother plays in the life of a daughter with facial differences, the project sought to broaden the scope of disability studies' literature to include how mothers influence their child's sense of self, from the perspective of both members of the dyad. Moreover, the project aimed to provide mothers the room to discuss in their own words the successes and challenges of raising a child with a difference, allowing them to personally acknowledge, without ridicule, the ways in which they feel their experiences are similar to or different from mothers of children without facial differences.

**Mothers with and without facial differences and the process of armouring.** A number of parallels can be drawn between the community of Black mothers and daughters and the community of mothers with daughters living with facial difference. Belonging to two minority identities, Black mothers and daughters maintain a "perilous social position in society" (Bell & Nkomo, 1998, p. 285). As such, African-American girls and women must acquire various skills to prepare them to withstand, negotiate, and overcome the numerous obstacles that society presents over the course of their lives. Specifically, they "must learn what it means to be a Black woman in a society that has not granted them the traditional 'courtesies for femininity'" (Greene, 1990, p. 211). According to Black feminist sociologists Bell and Nkomo (1998), armouring is a particular form of socialization whereby Black girls are taught the attitudes and "socially legitimate behaviours" for the two contexts in which they live, so as to develop a sense of psychological power that aids them in self-protection in the face of racism and sexism. By developing this armour, they are able to preserve a sense of dignity, self-respect, beauty and self-

worth, even when society's standards may seek to erode these qualities. In most cases, mothers are primarily responsible for "arming" their daughters; communicating with them about the roles they should adapt, expectations they should meet, and abilities and methods they should employ to flourish in a society that devalues them not only as women, but as Black women.

In the study by Bell and Nkomo (1998), mothers afford their daughters different types of armour, stemming from their own distinct values and experiences. Some mothers stress that their daughters be respectable by regulating their sexuality and carrying themselves in a dignified manner. Other daughters are taught to develop courage by developing their own individual beauty ideals and sense of style. Mothers also instill the belief that their girls can do whatever they want to do with poise and intellect. These messages are aided by selective exposure, whereby parents purposefully choose to subject their girls to activities and communities that reinforce positive self-images, boost social skills, and increase confidence. Daughters are also taught to be self-reliant, independent, and strong in the face of physical and emotional pain, often to the point of becoming "invincible".

Disabled women and girls are labelled with an identity that remains similarly devalued by mainstream society and are likewise denied "courtesies for femininity" (Greene, 1990), and as a result, may experience an erosion of self-worth over time. Considering this, girls with facial differences may be taught similar psychological strengths to defend their sense of self in a society that looks to erode it. Specifically, mothers may arm their daughters to face some of the social stigma associated with disability and difference. In my qualitative analysis of mothers and their daughters with facial difference, I examined whether armouring themes arose within focus groups and interviews, and explored how these messages may be communicated from mother to daughter, and the ways in which they are interpreted. I also sought to uncover the ways in which

the armouring used by women with facial differences differs from the armouring strategies found by Bell and Nkomo, given the unique experiences of daughters with facial differences, such as encounters with the medical system.

It is critical however, to make a distinction between the mothers and daughters within North American Black communities and those affected by facial difference. As Greene (1990) states: “It would seem logical that a young Black woman’s understanding of what it means to be a Black woman may...be heavily influenced by her mother’s phenomenological understanding of racism and sexism and their respective roles in shaping her mother’s own life” (p. 212). In this regard, young Black girls may look to their mothers as role models; women who have existed at the intersection of the same minority identities as they have. The same cannot always be said for mothers of girls with a facial difference. Like other young girls, as those with facial differences begin to struggle with “becoming women”, they seek out “like others” to envision their gendered selves. Without these role models readily accessible in their immediate social worlds, it becomes difficult for girls to experiment with gender, tomboyism, femininity, and other variations of gendered identities (Rice, 2014). Examining differences in armouring and other protective strategies used by mothers with and without facial differences in the lives of girls living with facial difference is therefore critical. Mothers who have personally struggled with developing a sense of femininity, faced social barriers associated with difference and disability, and been subject to repeated and intrusive medical practices may in fact be better suited to arm their daughters, as they speak from a place of experience. Therefore, the project incorporated both affected and unaffected mothers in the interview process, to compare and contrast their experiences of having a daughter with a facial difference, and to uncover their daughters’ insights around lessons of strength and resilience that both groups of mothers may or may not have provided them.

## Why Study Girls?

How a culture values or devalues physical features has a profound impact on women's sense of body and self (Rice, 2014). Over time and across many cultures, beauty has been considered the "province of women," and viewed as a gendered attribute of female desirability (Reisher & Koo, 2004). It is regarded as a positive and important component of self-image; an objective trait that all women desire to possess, as it makes them attractive to both peers and members of the opposite sex (Rice, 2014; Wolf, 1991). Moreover, in Western culture, "beauty" and "femininity" have become increasingly synonymous terms (Rodin, 1993), and as such, many disabled women are seen as undesirable and sexless, significantly impeding their ability to develop a positive sense of self (Rice, 2014).

Furthermore, many women with differences and disabilities believe that they exist at the intersection of two marginalized identities: both a woman and an individual with a disability (Rice, 2014). As such, issues with body image and sense of self may be intensified for these individuals as they are devalued by society in not one, but two ways. These feelings are summarized in a quote by one woman interviewed for Rice's study *Becoming Women* (2014): "Body image is a big issue for anyone with a disability but more so for women with disabilities. We are looked at as asexual and imperfect, and our bodies are viewed as being damaged and not worthy of love" (p. xxi). Altogether, the distinctive position occupied by women with disabilities and differences makes them an invaluable group to study.

While gender-specific data on facial differences are scarce, some investigators have put forth relevant findings on girls. Pope and Snyder (2005) conclude that girls with facial differences report more problems in the clinical range for social and thought problems. Girls with facial differences are also more likely to report dissatisfaction with appearance (Kapp 1979;

Leonard, Brust, Abrahams, & Sielaff, 1991), and endorse more feelings of sadness, loneliness, social withdrawal, and dislike by peers than boys (Pope and Ward, 1997). Parents also report that their daughters are more concerned about their appearance than sons (Turner et al., 1998).

Studying women during adolescence provides an additional level of complexity to the research project. A major task of adolescence is to form a unique and personal sense of identity; a process that involves developing an autonomous self in the context of close relationships (Grotevant & Cooper, 1985). As they transition through adolescence, children begin to examine themselves, discovering their beliefs, values, desires and dreams, in an attempt to develop confidence in their ability to move within the world (Bassoff, 1988; Steinberg & Sheffield-Morris, 2001). Many developmental psychologists argue that adolescence is a particularly risky and dramatic time for girls (Basow, 1992; Basow & Rubin, 1999; Brown & Gilligan, 1993). As young girls progress from childhood to adolescence, and become more independent and autonomous, many confront a crisis or impasse in their psychological development and begin to struggle with validating their sense of selves (Brown & Gilligan, 1993; Hill & Lynch, 1983; Stern, 1992; Thompson, 1964). As Brown and Gilligan (1993) state:

...at the edge of adolescence, we observed girls struggling over speaking and not speaking, knowing and not knowing, feeling and not feeling, and we saw the makings of an inner division as girls came to a place where they felt they could not say or know what they had experienced - what they had felt and known. (p. 13-14)

There also exists a reorganization of gender identity and ideals during adolescence. Young girls' attention shifts to focus on their own sexual attraction, and they begin to feel pressured to take an interest in their physical appearance and conform to what women are "supposed" to look and act like (Basow & Rubin, 1999). The pressure to conform to the Western ideal of beauty and femininity "depresses and disorients" adolescent women, and they are left struggling with

concerns about weight, fears of social rejection, and the desire to be feminine and “perfect”. Preoccupation with the body reaches an immense high in puberty, and girls become increasingly anxious about themselves, which results in more self-criticism, depression, dissatisfaction with their bodies, lower self-esteem and compromised academic achievement (Hill & Lynch, 1983; Pipher, 1994).

Adolescence is considered a time of “dual stress” when compounded with a chronic health condition (Beaune et al., 2004), particularly for girls. At a time when they feel a naturally increased strain to conform to society’s standards of attractiveness, and when beauty is highly valued for self-esteem, social acceptance, and dating, girls with differences and disabilities may begin to feel increasingly incompetent and devalued, experience negative self-perceptions, and isolate themselves (Bilboul et al., 2006; Snyder et al., 2005). For many women in Rice’s study (2014), adolescence represented the phase in life when they felt most separated from their bodies and distressed about self-image.

### **Experiences in Social Interactions with Known and Unknown Persons**

The cultural meanings and social values placed on people’s appearances, differences and disabilities have a profound impact on the development of their sense of bodily self (Rice, 2014). Modern Western society values the “body beautiful”, and within this context, people judge themselves and are judged by others, based on how they measure up to appearance ideals and norms, which are impossible to attain (Rice et al., 2003). Moreover, the negative cultural meanings associated with impaired bodies are prevailing in mainstream media; disabled people are not often depicted on television or in films, and where they do figure in the representational field, there is a disproportionate, negative emphasis on their difference, thereby perpetuating some of the prevalent myths that individuals with disabilities and differences are the

embodiment of evil and psychosis, or the epitome of pity and tragedy (Chatland, 2013; Reeve, 2006). Thus, given that Western society is so appearance conscious, places such heavy emphasis on attractiveness, and perpetuates negative stereotypes of differences, concerns around physical appearance are considerably greater or different for those members of society whose appearance falls outside what our culture considers “normal” (Reischer & Koo, 2004; Rumsey & Harcourt, 2004), including those with facial differences.

Frances Cooke Macgregor (1979) suggests that a visible difference is a “social disability”, as it is noticed by other people, and impacts the thoughts, feelings and behaviours of individuals living with one. Individuals with facial differences are often subjected to significant teasing and peer rejection in childhood and adolescence (Snyder, et al., 2005; Turner et al., 1997). They are also susceptible to hurtful name calling, offensive remarks, uncomfortable stares, “double-takes”, whispers, curiosity, personal questions, laughter, manifestations of pity, stereotyping, blatant avoidance in public situations, and even physical violence (Macgregor, 1979, 1990; Renooy et al., 1999). These aversive interactions occur in many settings, and most often in interactions with strangers (Macgregor, 1990).

Perhaps the most damaging reactive behaviour by strangers is staring. As Garland-Thomson (2006) summarizes, we stare at things that confuse us in an effort to make sense of something that is foreign. Staring is a forceful and sustained form of looking; a highly charged, voyeuristic, and intrusive way of reacting to another (Garland-Thomson, 2006; Rice, 2014). Staring is significantly different from gazing; while being gazed at may be considered a source of pleasure and power, stares carry negative emotions and meanings (Rice, 2014). It often serves to define a relationship between individuals with differences and those without. Staring is often

momentary, but nonetheless intimate and alienating, creating a power dynamic that serves to draw the boundary between “us and them” (Garland-Thomson, 2006; Rice, 2014).

The way known and unknown people respond in social interactions remain a significant source of stress, anxiety and pain for individuals who are affected by disability and difference, and has unique implications for each person and their sociability (Macgregor, 1990). The experience of negative social interactions may cause affected individuals to withdraw from and avoid social interaction in the future (Snyder et al., 2005), thereby impeding their ability to meet and relate to new people, make friends, and develop long term intimate relationships (Robinson, 1997). More importantly, as Macgregor (1990) argues, the reactive behaviours of unaffected strangers often generate feelings of shame, weakness, anger and humiliation, which can significantly erode the self-image and self-esteem of an individual with a facial difference. Through the negative messages conveyed in unfavourable social interactions, individuals with facial differences can come to believe that their face is unacceptable, and internalize the notion that they are inferior to others, unworthy, and deficient (Bilboul, et al., 2006; Renooy et al., 1999; Turner et al., 1998). The feelings of worthlessness and embarrassment that result from being stared at or demeaned by strangers can also prevent individuals from participating in society in the future (Reeve, 2004).

To date however, there has been very little research conducted on the ways in which mothers and other family members help children handle some of these negative social interactions with known and unknown people. Pope (1999) found that in families where children are taught to develop a “story” for explaining their facial difference to others early in life, the children are actually better able understand that their differences are not shameful, and are more likely to cultivate positive coping strategies for the future. Similarly, Klein and her colleagues

(2006) discussed how mothers of children with facial differences take a proactive role in helping their children overcome social limitations by: helping their child manage staring and teasing; talking to teachers at school; facilitating play dates with peers; and encouraging independence. In specifically addressing social interactions within the interview protocol, the present study aimed to build on these earlier findings, and uncover in more detail the ways in which mothers were involved in supporting their daughters' social interactions both throughout childhood and into adolescence and early adulthood.

### **Interactions within the Medical System**

Western culture is a medicalized culture, where disability and difference are considered the polar opposite of health, and identifiers of those members of society that are inherently unhealthy or "ill". Moreover, the culture posits that medical technologies are the sole way of "fixing" bodies that are "broken" (Rice, 2014). In our society, facial differences are framed primarily through a biomedical lens, which is premised on the notion that there exists a positive correlation between the severity of one's difference and the amount of psychological distress one experiences (Clarke, 1999). According to this approach, "normalizing" an individual's appearance will enhance their self-esteem, improve their "appearance ratings", and enrich their social interactions (Hughes, 1998). As Gilman (1998) argues, the rise in aesthetic surgery as an accepted practice reflects the popular societal belief in the medical system's ability not only to correct bodily deviance and deformation, but also to "cure" and "restore" the psyche that is damaged by the body's marginalization and stigmatization.

As such, individuals with facial differences undergo numerous surgical procedures over the span of their lives, are exposed to a number of medical professionals, and maintain high levels of contact with the medical system through routine hospital admissions, consultations, and

outpatient appointments (Charkins, 1996; Rice, 2014). While some treatments and surgical interventions do serve a functional purpose such as improving eyesight, hearing, and eating, many are aimed solely at improving appearances. Despite the popularity of various aesthetic treatments however, surgical intervention does not guarantee a “new” or “normal” face, but rather a transformation from one that is less presentable to one that is more presentable according to social norms (Pruzinsky, 1992; 2002).

Still, there has been a large amount of research that suggests that surgeries and treatments that look to improve physical appearance also have positive impacts on individuals’ self-perceptions. For instance, in their study with seventy children living with facial differences and their parents, Lefebvre and Munro (1978) used pre- and post-surgical interviews and questionnaires to conclude that reconstructive surgery “usually resulted in” increases in the child’s self-confidence, self-esteem, and overall satisfaction with appearance, whether or not the improvements were visible to outside observers. These findings parallel the results in other studies investigating the effectiveness of surgery in the lives of children living with facial differences (Clifford, Crocker, & Pope, 1972; Broder, Smith, & Strauss, 1992; Strauss, Broder, & Helms, 1988; Noar, 1991).

The exclusive emphasis on positive results and satisfaction with surgical procedures however, often overlooks practices used within medical systems that are invasive, aggressive, and frequently traumatizing. In her study, Rice (2014) reports that the bodies of research participants born with facial or physical differences were repeatedly looked at, forcefully touched, and photographed in health care interactions, most often without prior warning, or the individual’s and their family’s meaningful consent or permission. Individuals entering the medical system were also often subject to the “medical gaze”: the invasive looks of medical

practitioners that objectify their patients, regarding them as “problematic body parts rather than view them as whole human beings in fully contextualized psychological and social environments” (Davenport, 2008, p. 311). Oftentimes, medical professionals will overlook the feelings, experiences, and perspectives of the often frightened and embarrassed child being placed under their gaze (Rice, 2014).

Whittington-Walsh (2006) argues that this type of gaze is an expression of “attitudinal violence”: a demonstration of the institutional and cultural violence that follows from ablest views regarding the definitions of body “normalcy”. “Public stripping” is also a common practice in medical institutions whereby patients are subjected to medical photography that objectifies their bodies. Worse still, parents are often prevented from protecting and comforting their children through institutional practices that do not allow them to be present for procedures, intervene in clinical routines, or accompany their children on overnight hospital stays (Rice, 2014).

Practices within the medical system heighten patients’ feelings of physical vulnerability, diminish their sense of agency and control over their own bodies, and undermine their capacity to find value in their difference (Rice, 2014). Medical interventions are also a significant source of stress for children; according to Pope (1999), if these sensitive situations are not handled well by the families or professionals, children can experience traumatic reactions to the various procedures that may impair their ability to devote energy to accomplishing normal childhood tasks. The “medical gaze” and “public stripping” have consequences similar to those included in Garland-Thomson’s (2006) review of staring: they invalidate the individual; invade their sense of body boundaries and privacy; and create an alienating power dynamic, marking the boundary between the “healthy us” and “sick them”. Moreover, the language used within the medical

system (i.e. deformity, abnormality, anomaly, disfigurement) serves to perpetuate the idea that disabled bodies are limited and flawed. Through frequent contact with medical professionals who use this language, the invalidating messages conveyed can be internalized by the individual and they can come to view themselves as unhealthy, imperfect, and inadequate (Rice, 2014). Thus, maintaining a positive sense of self is difficult when forceful, invasive and aggressive clinical practices continue to indirectly communicate that individuals living with physical differences and disabilities are not as deserving of consideration or respect as those who are not.

Interactions within the medical system can also be particularly stressful for parents raising children with facial differences. In the one existing study that explicitly examines parents' experiences of treatment for facial differences, Nelson and her colleagues (2011) determined that medical interventions, particularly surgery, were experienced as a constant source of tension. While parents recognized that surgery could make improvements to a child's overall functioning, and "normalize" their appearance, agreeing to numerous surgeries went against their natural instinct to protect their child from distress and discomfort. Experiences within the medical system were emotionally-charged for parents, and yet, many strived to present "a strong outward demeanor" for the benefit of their children (Nelson, Kirk, Caress, & Glenny, 2011, p. 351). The physical and emotional impact of surgery on their children was also both anxiety- and guilt-inducing for parents.

Moreover, a large amount of uncertainty accompanied interactions with the medical system: parents were often unsure of the type and amount of treatment their child would receive, and had a difficult time understanding what the long-term outcomes of their child's surgeries would be. Thus, most parents attempted to deal with their doubts and insecurities by adhering closely to the recommendations put forth by the medical teams with whom they interacted, and

place trust in the practitioners who provided their children with care (Nelson et al., 2011). These findings put forth by Nelson and her colleagues echo those in other literatures in which children's medical treatments are viewed as intensely emotional and challenging experiences for parents (Callery, 1997; Jordan, Eccleston, & Osborn, 2007; Maciver, Jones & Nicol, 2010; MacLaren & Kain, 2008; Sobo, 2005). Altogether, the stressors that children and youth face in undergoing numerous difficult medical procedures, discussed above, combined with the heightened emotions and pressure that parents contend with while navigating their child through the medical system may significantly impact the way the parent-child relationship is negotiated and experienced by both parties.

To date however, there exists no research on how parents help their children living with facial differences prepare for and cope with experiences within the medical system. Beyond Traustadottir's (1991) research on the gendered ideology of care in disabilities, there is very little discussion around the roles that mothers specifically assume in navigating this system alongside their children, and no existing knowledge on the way that children interpret their mothers' efforts in this area of their lives. The present study sought to attend to this gap in research by highlighting the ways that both mothers and daughters touched by facial differences experience the medical system, and explicitly addressing how mothers involved themselves in their daughters' medical journey.

### **The Impact of Facial Difference on the Family**

According to Turner and colleagues (1998), given the social and medical challenges that children living with facial differences encounter, the family environment is critical to their healthy physical and psycho-emotional development. The literature that explores the impact of facial difference on the family unit spans two broad areas: attachment processes between the

child and their caregiver, and the family's adjustment to a child's difference. Each of these have significant implications for a child's self-esteem, confidence and overall sense of self.

**Attachment.** The first overarching theme in the literature focuses on the child's attachment with their parents, namely his or her mother. Psychological scholarship to date heavily emphasizes the importance of attachment in development, often suggesting that a warm, responsive relationship with parents in early childhood is crucial to a child's healthy psychological adaptation (Pope, 1999). Being responded to with accuracy and sensitivity is said to be especially important to babies with health concerns, who may require extra care and attention (Maris et al., 2000; Pope, 1999). As such, attachment patterns between parents and their children remains one of the most popular areas of study in empirical studies on facial differences.

A number of studies demonstrate that rates of insecure attachment are higher between parents and infants with facial differences (Maris et al., 2000; Pope, 1999), and attribute the disruptions in relationships to a number of processes. For one, accurate responsiveness may be difficult as facial expressions of a child with a facial difference can be challenging for parents to read (Speltz et al., 1994). Parents may also find it difficult to respond to their child with warmth given the potentially negative emotional responses they may have to the unusual appearance of their child's face (Field, 1995). Similarly, as parents adjust to having a baby with a facial difference, they may be unable to transition away from their guilt or shame about their child's difference, and their own negative emotional responses to it, and appropriately attend to their child's needs (Pope, 1999). Alternatively, Wasserman and colleagues (1986) propose that mothers may initially attempt to interact excessively with their children to compensate for their

child's difference, and consequently "burn-out", leading to extended periods of mother-infant detachment, which destabilizes the relationship overall.

Attachment theory has emphasized the significance of experiences and relationships in the early stages of a child's life, recognizing the importance of building warm, trusting, sensitive relationships with parents. Building a secure relationship with one's primary caregiver early in life is said to help a child develop confidence in other's caregiving abilities, to believe in their own worthiness, and to allow them to navigate the social world successfully on their own, teaching them what they can expect of all future relationships (Maris et al., 2000; Pope, 1999). Without these lessons, children may struggle to develop self-control, and experience difficulty forming relationships later in life (Speltz et al., 1994), impeding their ability to develop a positive sense of self. As Speltz and colleagues (1994) suggest, these outcomes are commonly displayed by children, adolescents and adults with facial differences. However, while there does exist a wealth of literature on attachment between parents and their adolescent children (Allen, 2008; Buist, 2012; Rice, 1990), research on facial difference has yet to explore parent-adolescent attachment and relationships, thereby eliding a critical stage of human development. Moreover, the overemphasis on attachment in the facial difference literature can be problematic given that it overlooks other aspects of relationships that are essential to developing a well-rounded understanding of relational processes in families touched by disabilities.

The present study sought to reframe mothers' roles in facial difference research by looking beyond attachment processes, and giving mothers the opportunity to reflect on their experiences of building a relationship with their daughters in adolescence, rather than infancy and early childhood. It also aims to explore the ways in which the mother-daughter bond is influenced by other relationships and systems that surround it.

**Family adjustment.** The second theme in literature on facial difference and family dynamics is the process of adjustment within families. The birth of a new baby with a visible difference leads many parents to experience unexpected reactions and challenges (Rumsey & Harcourt, 2004; Walters, 1997). The experience of giving birth to a child with a facial difference may give rise to a wide range of intense emotions including grief, anger, disappointment, anxiety, guilt, depression, confusion and protectiveness (Bradbury, 1993; Lansdown, 1981; Slutsky, 1969; van Staden & Gerhardt, 1995). Due to the unique and highly variable needs of children with facial differences, parents are also responsible for providing “extraordinary levels of care” for a number of years (Topolski, et al., 2005). This expectation, combined with increased levels of parental anxiety around their child’s condition, can promote parental overprotectiveness and compensatory behaviours, particularly in mothers, with whom this research is often conducted (Klein, et al., 2006; Rumsey & Harcourt, 2004; Richman & Harper, 1978; Speltz et al., 1994; Speltz et al., 1995). It is important to note however, that there exists a wide range of responses to the arrival of a baby with a facial difference, and that parents vary in their ability to adapt based on their background and available coping strategies (Bradbury & Hewison, 1994; Charkins, 1996; McWilliams, 1982).

Parents’ ability to adapt to and cope with the challenges that facial differences pose is critical for the psychological health of their children (Bradbury & Hewison, 1994; Endriga & Kapp-Simon, 1999). The emotions, attitudes, and expectations that parents display in response to their child’s condition convey their acceptance of their child’s appearance (Pope, 1999; Turner et al. 1998), and these responses are internalized in much the same way as reactions from strangers in social interactions, undoubtedly influencing the child’s perception of their own difference. Depending on how a parent or family member adjusts, children may come to understand their difference as something to be ashamed of; as something that makes them undeserving of love.

The need for parental sensitivity about *what* is communicated to their child about appearance and *how* it is communicated are critical in all stages of development, as self-concept can be influenced in childhood, adolescence, and even into adulthood (Pope, 1999). One of the fundamental objectives of the present study was to uncover what mothers are communicating to their daughters about appearance, explore how these messages are being conveyed, and understand the impact that they have on their daughters' developing sense of self.

Much of the literature on how families are impacted by facial differences reviewed above is informed by the deficit model of disability. It is assumed with these frameworks that by possessing a disability or difference, the individual's quality of life must be reduced (Rice, 2014). Disability and difference are framed as insurmountable, permanent barriers to a "normal" life, often serving to strip the affected individual of a sense of dignity, invalidating their unique sense of bodily self, and failing to acknowledge the valuable insights and understandings living with a disability or difference might bring. Given the relational nature of disability, families of those who are touched by disability and difference are also subjected to the same stigma, oppression and perceptions of reduced quality of life as those living with differences routinely encounter (Austin, 2009). Rather than situating the individual and family in context, the literature views the parent-child relationship as pathological by focusing exclusively on the problems faced by individuals and families with facial differences.

According to disability theorists, suggesting "disabled families" are dysfunctional serves to marginalize the family and the individual in a time when they require social support (Read, 2000; Ryan & Runswick-Cole, 2008). Additionally, these conventional views of families are overly-simplistic and individualistic; they fail to address how families negotiate an understanding of their child's disability or difference, and elide the pressures of disablement

from society that exerts a damaging influence on familial relationships (McLaughlin, Goodley, Clavering, & Fisher, 2008). For Cole (2004), it is not the process of caring for a child with disabilities that is distressing, but rather the barriers that families have to face when accessing services and support that destabilize the familial unit. Moreover, while some of the difficult experiences mentioned above are surely real for a number of individuals, they do not provide an accurate or complete account of all families. In fact, research from within disability studies suggests that families today are better able to see impairment as part of the continuum of human experience than those forty years ago, and as such, consider their family dynamic ordinary rather than “special” (McLaughlin et al., 2008).

Past research has also failed to consider the ways in which individuals and families affected by facial and other bodily difference creatively navigate and overcome disabling barriers encountered in the surrounding world. Thus, scholars in disability studies recommend that research begin to shift away from a deficit model of disability and towards highlighting what Pope (1999) calls “points of opportunity”; instances in which the family affected by facial difference finds effective ways of dealing with the challenges it faces, which might enhance the child’s potential for adaptive psychological adjustment. For instance, Meyerson (2001) suggests family support, faith, and humor are factors that influence resilience in children with facial differences. Likewise, Ellis and Hirsch (2000) suggest that families believe having a child with a difference promotes adaptive characteristics in parents; Murray (2000) states that parents experience their children in positive ways; and McLaughlin et al. (2008) assert that parents become uniquely in-tune with their children.

Studies such as these that look to acknowledge the unique and adaptive ways that individuals and families flourish can enlighten researchers and clinicians to a new way of

thinking about facial difference. The present study sought to build off of these more recent studies within disability literature and focus on similar “points of opportunity” in the community of mothers raising daughters with facial differences. While still acknowledging the potential challenges that the dyads encounter within their relationship, the study aimed to recognize and highlight the ways that mothers and daughters effectively deal with the disabling pressures exerted on their daily lives, and negotiate their own unique understandings of living with and raising a child with a physical difference.

Finally, it is important to recognize that literature on families impacted by facial difference often focuses on families in which only a child is affected. This however is not entirely reflective of the diversity in families touched by facial difference. There are a percentage of families in which both a parent and the child have a facial difference, and this may impact the child’s self-image and the parents’ perceptions and experiences in raising him or her. However, it is worth noting that of the studies reviewed for this paper, none included discussions of the experiences of families with parents who are also living with facial differences, and thus, there remain a number of diverse perspectives to be explored. Therefore, the present study aimed to address this gap in research, and interviewed dyads in which both the mother and daughter have facial differences.

## **Theoretical Frameworks**

### **Embodiment Perspective**

In North American society, disability is viewed through a medical lens; it is considered an abnormal or pathological functional impairment that reduces an individuals’ quality of life; a deviation from the assumed norm of the human body that requires medical intervention. In response to the medical model, early disability studies scholars put forth the social model of

disability, wherein they theorized disability as a problem located not in the body but in the social world (Rice, 2014; Silvers, 2013). The social model distinguishes between ‘impairment’, defined as a difference in an individual’s mental, physical or sensory functioning, and ‘disability’, which results entirely from social structures, built environments, and communication technologies that exclude people with impairments, and provide segregated or below standard provisions for inclusion (Northern Officers Group, 1999; Rice, 2014). According to the social model, exclusionary practices, and attitudinal and physical barriers that prevent individuals with impairments from taking part in everyday life ultimately ‘define’ who is disabled and who is not in any given social context. From the perspective of disability scholars and activists who operate within the social model, the disadvantages that individuals living with disabilities experience can be eliminated through the reform of oppressive societal practices and structures (Silvers, 2013).

According to Morris (2001), the social model is beneficial to the study of disabilities as it becomes possible to talk about the limitations individuals with disabilities face without pathologizing people or suggesting that modifications be made to their bodies. However, the prevailing models of disability, whether medical or social, fail to acknowledge individuals’ personal experiences of ability and disability, normalcy and difference, and pain and pleasure. In other words, both the social and medical models of disability have been critiqued for ignoring the distinctive meanings that people assign to their bodies and the embodied experiences that shape their identities and sense of themselves (Rice, 2014; Turner, 2001). This is particularly problematic, given that one cannot study individuals without studying the bodies they inhabit.

To address issues with the medical and social models, critical disability theorists have offered the idea of embodiment or the “embodied self”, which focuses on the inseparability of the body from the person. An embodiment perspective asserts that people do not form their

subjectivities in isolation of their bodies, but rather that their bodies are vehicles for exploring their selves in the world (Rice, 2014). According to the embodiment perspective, disability is a complex, “multifaceted” experience of the bodily self that is unique to each person; a blend of their own perceptions and others’ understandings of difference (Lutz & Bowers, 2005). In most of the current literature on embodiment, it is assumed that all human beings inhabit their bodies and move through the world in similar ways (Garland-Thomson, 2007). However, disability theorists assert that people with disabilities may inhabit their bodies in radically different ways than those without disabilities and that the ways in which people experience the world is critically influenced by their unique embodiments (Turner, 2001). While individuals living with disabilities and differences develop numerous innovative strategies to live within their bodies in an unwelcoming social world designed by members of the dominant group, these stories have been largely ignored by previous research on disability, stripping individuals of their subjectivity and agency (Zitzelsberger, 2005).

The present study assumed an embodiment perspective and recognized that the unique subjectivities of each female participant were shaped by her ‘embodied self’; by both her experiential awareness and others’ understanding of her facial difference. Moreover, the study acknowledged that all of the women’s stories would be different and sought to attend to their distinctive experience of body and self rather than assume all individuals with facial differences navigate self-making in similar ways based on shared differences, which remains common practice in much of the existing literature on facial difference. In the present study, I encouraged each young woman to share her unique experiences of living with a difference, and the ways in which she felt she came to develop and understand her own sense of self. Similarly, I encouraged each of the mothers to discuss the distinct ways in which they have navigated raising a child with a facial difference.

## **Feminist Disability Theory**

A blend of disability studies and feminist theory, “feminist disability studies” informs and frames the “My Mother, My Daughter, My Self” project. Feminism has critically examined categories of “woman”, “man”, “feminine” and “masculine” as it tries to de-stigmatize woman and de-stabilize gender and sex binaries in patriarchal society. Similarly, disability studies has critically interrogated the terms “disability” and “normalcy” with the intention of integrating individuals with bodily differences into society (Garland-Thomson, 2002). When applied together, each of these theoretical frameworks serves to enrich the other: feminist theory offers disability studies “profound insights, methods and perspectives”, while disability studies provides an understanding of disability as a social category of analysis that can “deepen, expand and challenge” feminist theory (Garland-Thomson, 2002, p. 2-3).

As its own theory, feminist disability studies is rooted in one founding principle: that disability, much like femaleness, is not a natural state of weakness, inferiority, insufficiency or misfortune (Garland-Thomson, 2002). Instead, it critiques the reductive, biological understanding of disability and gender, and posits that both categories are socially constructed, cultural interpretations of human variations (Garland-Thomson, 2005; Hall, 2011). According to feminist disability theory, women and people with disabilities have historically been viewed as inhabiting aberrant and deviant bodies that fail to meet the implicitly white, male, and able-bodied standards of normalcy; in this regard, the same attitudes about the body that have contributed to women’s oppression also contribute to the psychological subjugation of those with disabilities (Wendell, 1989). Intersectionality is thereby also central to feminist disability studies since disabled women struggle with disability and gender oppression (and possibly other oppressions) concurrently. As Garland-Thomson (1994; 2002) argues, it is imperative to

understand the ways in which experiences of disability interact with sexism because no woman is ever “just a woman”, but instead occupies several cultural identity categories.

Feminist disability studies looks to confront and challenge the prevalent assumptions of living with a disability in society; critique the historical, social, cultural and political forces that suggest disabled lives are unliveable; give voice to the individuals whose experiences have been misrepresented or ignored; understand the relationship between the body and identity; and addresses questions of gender, embodiment, appearance, and medicalization (Garland-Thomson, 2002; 2005; Hall, 2011). Moreover, feminist disability theory suggests that we are better off learning to accommodate and appreciate bodily differences than trying to eliminate or deny them because they come with their own unique knowledge (Garland-Thomson, 2002). It engages in two critical practices. First, it avoids the use of impairment-specific terminology or categories to discuss disability, and instead focuses on the meaning attributed to bodies. Second, it attends to language when referring to disability to ensure that it does not reproduce notions of disability as inferior or abnormal (Garland-Thomson, 2005). Feminist disability studies informs the research objectives and assumptions of the present study, especially by attending to participants’ intersectional identities and by using language to convey that facial difference is not a natural state of inferiority.

### **Contributional Perspective**

Within the contributional perspective, disability and difference are investigated in terms of the value they may add to individuals, family relationships and to communities. A contributional approach seeks to empower individuals living with facial differences, by uncovering and illuminating how they accept and work within their circumstances. Most importantly, it seeks to “open up the end of the continuum beyond normalization” and

acknowledge that individuals and families living with a disability or difference have uniquely valuable experiences (Eiserman, 2001).

The use of this model in facial difference research stems from Clifford's (1983) claim that science overemphasizes the potential pathology and deviance within the community of individuals living with facial differences, rather than discussing what living with a facial difference means to the person and their family. In Eiserman's view (2001), deficits tend to be the primary focus when studying facial difference because of the nature of the medical model. Given the amount of literature focusing on the negative repercussions and pathology of facial differences, it was vital to provide the participants in the present study the opportunity to discuss some of the positive contributions that having a facial difference has made towards their sense of self and their relationship with their mother. The interviews served as a unique occasion for mothers and daughters living with facial differences to reflect on their specific experiences and view their lives through a positive lens. However, the contributinal perspective has been criticized for focusing too heavily on the positives, thereby ignoring a significant aspect of living with a disability or difference such as the challenges of social interactions (Eiserman, 2001). This project sought to apply a contributinal perspective by balancing an understanding of the barriers and challenges associated with living with a facial difference with an appreciation for the knowledge and skills girls and young women develop in navigating an often evaluative and alienating social world.

### **Positionality**

Having a mother working in the field of disability services and advocacy was extremely beneficial in beginning and maintaining my involvement within the community of individuals living with facial differences. I believe that in being exposed to individuals who look different

very early in childhood taught me to value individuality, and to promote acceptance in my later years. In the last ten years, I have become actively involved with the Toronto-based organization AboutFace, a national charity that supports individuals and families touched by facial differences. I have come to meet a number of wonderful people, many with whom I maintain working relationships and friendships. I can recognize and name numerous conditions and have come to learn about the various treatments and surgeries that many of individuals have had to undergo. In working closely AboutFace, I feel I have acquired a keen sensitivity and appreciation for physical differences and disabilities.

Moreover, I feel these experiences led me to formulate a number of questions, particularly around relationships. In being part of the AboutFace community and networking with many individuals, I have been privy to some of the social barriers that individuals with facial differences encounter every day, and the way they are subjectively interpreted. I have also been a part of creating, editing and delivering various resources to support individuals living with facial difference and their parents. It has always interested me to know how these resources are used by mothers and fathers, and how they are received by their children. I have also often wondered what makes the difference between strong and conflicted parent-child relationships, and how parents' actions and responses influence a child's sense of self. As such, my early experiences have served as the basis of my graduate education.

Given my unique involvement within the facial difference community, there are many ways in which I consider myself existing on the inside. I believe I can discuss facial difference from a place of knowledge and insight, in a manner that is both positive and respectful. Yet the reality is that I am on the outside: I do not have a facial difference. As much as I have friends with facial differences, we do not currently share the experience of marginalized identity, and I

still have plenty to learn. I may never truly understand what these individuals continue to encounter on a daily basis. It is vital for me to continuously acknowledge this fact as it helps to shape my research, and heightens my awareness of my language, which conveys its own specific messages. While using the term “them” can in some ways serve as recognition that I do not live with a facial difference, it can certainly be interpreted as “othering” and implies that I see facial difference as “abnormal”. There have been many instances where I catch myself using pathologizing language, even though I understand how damaging this can be. Without an insider perspective, I admit that it is sometimes difficult to recognize how disability is constructed by society. It is equally difficult to conceptualize the individual meanings of living with a difference and truly take on a critical, feminist, or embodiment perspective without sharing in these lived experiences. At the same time, I share in the belief adopted by many sociologists that researchers need not share in a marginalized identity to conduct insightful research about a specific marginalized experience, but rather, that researchers continuously strive to be actively engaged, aware of their location, and humbled by the knowledge and experience of their participants (Adler & Adler, 1987; Angrosino, 2005; Asselin, 2003; Dwyer & Buckle, 2009; Fay, 1996; Mullings, 1999; Kanuha, 2000; Rose, 1985).

While I currently do not live with a facial difference, I feel I occupy a uniquely valuable position. In my involvement in the community and through meeting people and learning about facial difference, I have become open to what I hear and read, always willing to consider and appreciate the positive aspects of living with a facial difference, and be open to perspectives that may not always be recognized or surfaced in the empirical research. Similarly, being on the outside, I can also appreciate what non-affected people can think and feel when they are confronted with bodily difference. Yet, it is vital that I continue to ask myself how my background and present social location influences how I experience individuals with a facial

difference, and what I emphasize in my research. As a responsible researcher, I must be open to the stories each woman shares, and allow them to give their individual experiences meaning. It is then my job to interpret their narratives in a way that validates and values who they are and what they have lived.

## **Methodology**

### **Participants**

Ten daughters, ages 13-22, living with facial differences, were recruited for participation in the study. In total, 12 mothers were also recruited to participate, ten of whom were the mothers of the young girls who elected to participate. One daughter also had her step-mother participate, given that she had been involved in her life since before she was a year old. One mother's daughter did not participate in the study as she resided overseas. All mothers and daughters were recruited from within Canada, except one mother recruited from the United States. All but three of the participants were Caucasian; one daughter identified as Aboriginal and Caucasian, and one mother-daughter pair were Asian-Canadians. All but one of the daughters had congenital facial differences, including: cleft lip and palates, port wine stains, Cruzon's Syndrome, Treacher Collins Syndrome, Goldenhar Syndrome, and Hemifacial Microsomia. One daughter had an acquired facial difference resulting from Juvenile Arthritis. Three of the twelve mothers were also living with the same facial differences as they daughters (Cleft lip, Port Wine Stain and Treacher Collins).

The age range of the daughters was selected as it falls within the definition of "adolescence" put forth by Steinberg & Sheffield-Morris (2001) and because it includes both earlier (13-15) and later adolescence (16-19). It also incorporates the first few years of emerging adulthood, another period of "profound change and importance" for young people (Arnett,

2000). Altogether, covering the a wide range of ages helped to provide some diversity in the daughters' experiences and responses, and allowed the project's research questions to be answered from more than one perspective. The younger girls (ages 13-15) were actively engaged in the process of self-making, puberty, resolving family and peer relationships, and beginning high school, and were therefore able to provide insight into their present experiences and challenges. The older girls (ages 16-22) are more actively involved in new issues or transitions such as intimate relationships, sexuality, and employment, and were better able to speak to and reflect upon some of their unique experiences both past and present. No other inclusion or exclusion criterion was imposed for the participants.

### **Participant Selection**

Participants were recruited through AboutFace, a support and information network for people with facial differences, located within Toronto. Within their 25 years in operation, AboutFace has compiled a large database of children and adults with facial differences in North America. A consultation was held with the AboutFace staff and Board of Directors to inform them of the purpose of the project and to address ethical questions. The Marketing and Outreach Manager was provided with my personal contact information, a summary of the proposed project, and the participant inclusion criteria in an email script (See Appendix A) and distributed the information to the entire database via email. The email stipulated that the research project is not in any way affiliated with AboutFace, and that participation or refusal to participate in the study would by no means interfere with their access to AboutFace services or resources. It also stipulated that interest in participating in the project should be sent directly me and not to AboutFace. The organization assured all possible participants that their identities would remain entirely confidential and would not be disclosed to any staffer or other member of the

organization. Given that participants were accessed through the AboutFace database, potential participants may have felt a potential invasion of privacy. However, greater social risk was avoided as the decision to contact me remained entirely with the potential participant and no personal or private information was provided without participants making first contact.

All potential participants who contacted me were screened to ensure they met the criteria, and that both the mother and daughter were interested in participating in either a focus group or one on one interview. They were then sent a letter of informed consent or proxy consent (for adolescents under the age of 18) to be signed and returned to the researcher. A copy of the letters of informed consent for women and youth can be found in Appendix B and C. For those who elected to participate in a focus group, details regarding the date, time and location of the focus group were provided to each participant upon receipt of their consent forms. For those participants who elected to participate in a one-on-one interview, a date and time were set, based on my availability and the participant's availability, to conduct an in-person, telephone, or Skype interview. Data collection ran from January to March 2014. Each mother and daughter received a \$20 gift card to Starbucks, Indigo, or Tim Horton's in appreciation of their participation.

## **Methods**

While focus groups were initially the intended method of data collection for the study, given that they are considered an interactive, time and cost-efficient means of collecting qualitative data that foster a safe and open environment for participants (Krueger & Casey, 2000; Morgan, 1997; Vaughn, Shum, & Sinagub, 1996), the majority of participants were unable to participate in a group due to their location or various scheduling conflict. A number of participants also expressed more comfort responding to questions and disclosing personal

information in private. Therefore, the ability to conduct one-on-one interviews was also offered to all participants.

Two mother-daughter dyads agreed to participate in a focus group, thus, two small in-person focus groups were held: one with the daughters (age 16 and 17) and one with their mothers. One focus groups lasted approximately an hour and thirty minutes, while the other lasted two hours and twenty minutes. The remaining eighteen participants elected to participate in one-on-one interviews, given their location and their comfort disclosing personal information in the presence of others. In total, ten interviews were conducted by phone, and eight interviews were conducted via Skype. Interviews ranged from twenty-five minutes in length, to two hours and twenty minutes in length, with an average running time of approximately fifty minutes. There was little difference in quality between the in-person focus groups and the telephone or Skype interviews; mothers and daughters shared their personal experiences in the same amount of detail. However, it seemed as though the mothers interviewed in-person had augmented emotional reactions to more questions than those mothers who were not interviewed face-to-face.

The mothers and daughters were interview separately to maximize both mothers' and daughters' comfort with disclosing personal information and attitudes. Both the daughter and mother interviews covered the same topics and posed the same questions; however, the questions were restructured so they were directed at each group. A complete list of the interview questions for daughters and mothers can be found in Appendices D and E. The first section of questions directly related to answering the first research question regarding mothers' role in the various systems. The second section of questions related to the second research question addressing mothers' role in their daughters' adolescence, while the third and final set of questions attended

to the contributions of facial difference to the life of both the daughter and mother, as well as their relationship.

### **Ethical Considerations**

This research study was approved by the Research Ethics Board at the University of Guelph (See Appendix F). Participants were made aware of the purpose of the study upon recruitment. It was also reiterated within the letter of informed consent or proxy consent, and at the start of each focus group and interview. No deception was used over the course of the study. Individuals were informed in the selection phase and at the start of the interviews that they could refrain from answering any question they wanted, and reserved the right to withdraw their participation at any time. It was also conveyed that should a participant wish to withdraw, attempts would be made to address and resolve whatever questions or concerns they may have had, and if the participant still wished to withdraw, they would be permitted to leave the focus group, or end the interview, and all responses to previous questions would be omitted from the transcripts. Fortunately, no participants elected to withdraw from their interview, and all questions were responded to.

Focus groups and interviews were recorded on a digital recording device. The audio recording was transferred to a password protected, encrypted laptop within 24 hours of the completion of the interview. I transcribed each of the interviews myself, with all names changed to protect the identity of the participants. In many cases, the pseudo names used were selected by the participants themselves, so that they could be identified in the final report. The recordings were deleted from the laptop immediately following the completion of transcription. All printed files were kept in a locked cabinet in my home or office at the University of Guelph. Transcripts were also sent to each participant so that all data collected could be verified and reviewed before

analysis began; mothers and daughters were only sent their respective transcript to ensure the responses of each individual remained private. All hard-copy files were shredded upon completion and submission of the final dissertation to the department for graduation. Transcripts however, remain on my laptop for use within a doctoral thesis.

### **Data Analysis**

The transcripts of collected data were analyzed using thematic analysis outlined by Braun & Clarke (2006), a method that provides a rich, detailed and complex account of qualitative data. As discussed by the authors, thematic analysis is used to identify and analyze patterns of meaning within a data set, organizing and describing its content in detail. The use of thematic analysis within the study is consistent with its phenomenological epistemology, whereby it values the subjective experiences of each participant and aims to understand individuals' everyday experiences of reality to gain insight into living and raising a child with a facial difference (Smith et al., 1995).

The analysis of the data was a delicate balance of both inductive and deductive approaches: the themes identified are strongly linked to the data itself, with efforts made to avoid fitting them into pre-existing conceptions of the research question; however, the data was coded for specific research questions undoubtedly driven by my theoretical and analytic interests and prior engagement with the literature (McLeod, 2001; Patton, 1990). Moreover, the themes identified within the data were nested at both the semantic and latent levels of analysis, such that both the explicit, surface meanings and underlying ideas and assumptions within the data are highlighted (Boyatzis, 1998).

The analytic process moved through various stages, adhered to the steps outlined by Braun and Clarke (2006) as a guideline. I first familiarized myself with the data through the

process of collection; therefore, I came into the analysis stage with some prior knowledge of the data and some initial analytic thoughts. I proceeded with analysis by immersing myself in the data through transcription and repeatedly reading the final data sets in an active way, including highlighting and note-taking. Codes were generated by hand around features of the data that were of particular interest, and the data was organized into meaningful groups that were both data- and theory-driven. Codes were then combined to form overarching themes that were validated by the data, but also internally homogenous (cohered to one another) and externally heterogeneous (distinct from one another).

I transcribed interviews from both the daughters and mothers, and these were treated as two independent data sets. The themes in the daughter and mother interviews were analyzed independently to provide both a comprehensive description of both data sets. This primary analysis was followed by a comparison of the daughter and mother data sets to identify consistencies and disparities between the themes put forth by both groups, as well as to discuss potential significance and their meaning in the context of the mother-daughter relationship. The transcripts from both the mother and daughter data sets were also reviewed in an additional analysis to isolate the experiences of the dyads in which the mother also has a facial differences and those in which she does not.

As described above, the first section of data was coded for themes in response to the first research question: how do mothers support or hinder daughters in navigating through the various experiences that are common in the lives of individuals with facial differences (i.e. family adjustment, social interaction, and medicalization)? The second section of data was coded for themes responding to the second research question: in what ways do mothers encourage or impede their daughters' adolescent development, particularly the development of their sense of

self, body and gender? Themes pertaining to the third research question regarding the contribution of facial difference to the mother, the daughter and the relationship, were identified by reviewing and coding both data sets in their entirety, with particular attention paid to section three of the interview.

Finally, in the second stage of analysis, the data was parsed into two new sets: one including interviews from daughters and their mothers who are also living with a facial difference, and one including interviews with daughters and their mothers who are not. Coding of each complete data set was completed, and the themes identified by the two groups were compared to one another to answer the fourth research question: is there a difference in the experiences of the mother-daughter relationship when the mother is also living with a facial difference? Throughout the analysis, the individual voices of both the daughters and mothers were honoured and highlighted using direct quotations from within the transcripts to validate the themes that are discussed.

## **Results**

### **Role of Mothers in Systems**

Given the focus on social interactions, the medical system, and the family network in the previous literature on facial difference, the first objective of the study was to understand what role mothers' played in the social, medical, and familial realms of their daughters' lives from the perspective of both members of the dyad. There was also some frequent discussion of mothers' role in relation to the media; a system not directly targeted with the interview questions, but addressed by mothers and daughters unexpectedly.

Overall, there were significant consistencies within the information provided by the mothers and the daughters in response to the interview questions pertaining to this research objective, and many of the same roles were discussed across the mother-daughter pairs, despite the variability in the types of racial differences and family structures. These roles however, were not without their own difficulties: mothers and daughters alike discussed the way in which they felt the roles assumed were complex, and complicated their day-to-day life, or caused conflict in their relationship with one another. The roles assumed by mothers in the social system, medical system, family system and media will be discussed at length in the following section using excerpts from the interviews with mothers and daughters to support presented claims. The presentation and description of the roles will be followed by a discussion of the various tensions mothers and daughters felt were associated with some of these roles.

**Teaching and learning to talk back: Navigating social interactions.** Daughters and mothers discussed a number of social experiences that were all considered together as part of the social system. In most cases, this realm included: the education system (including pre-school, elementary school, high school, and in some instances, university); friendships through various stages of development; and interactions with strangers in public arenas. Throughout the interviews with the mother-daughter dyads, it became clear that mothers assumed three important roles in their daughters' social life: the coordinator, the educator, and the defender.

***“Trying to keep her connected”:* The co-ordinator.** One of the most prominent roles that mothers assume is their daughter's social co-ordinator, especially in the early years. While the daughters recognized that their mothers did take on this role, they rarely elaborated on reasons why they thought their mothers made coordination such a priority. Mothers however, often discussed this role stemming from a place of concern; a necessity to protect their daughters from

social isolation. For example, Beth, the mother of a 13 year-old stated, “She’s left out otherwise,” and Ellen, the mother of a 17 year-old noted: “I will do things that most parents probably wouldn’t do because it’s always at our forefront that social issues are very important, and keeping her socially active because she has a bit of an anxiety issue.” Lee, the mother of a 16-year old also suggested: “I’m sure this happens to a lot of high school kids...but I think our worry is, because of the difficulties with her speech and her hearing and the way she looks, it’s more emphasized...we tend to jump in more.” Margaret also reflected on her 21 year-old daughter’s experience saying, “She probably did isolate herself, so my piece was mostly trying to bring her out...trying to keep her connected.”

The majority of mothers often took charge in ensuring that their daughters had a group of friends that they were involved with; either initiating contact with their daughters’ peers, encouraging their daughters to engage with other children, or making their daughters part of a community group that fostered close friendships. Over time, these mothers also sought to become familiar with their daughters’ group of friends and their families. For instance, Ellen mentioned: “Now that she’s in high school, I encourage her to...anything she’s invited to, to go.” Beth also noted: “I instigate everything. I have her in...a Christian Girl Guides almost. The girls there are really good and include her.” Lee asserted: “I know of her friends. She’s not at the same school that a lot of her buddies went to. Those guys I know really well because I knew them since they were like, yay-big.” Maureen, who has a 22 year old daughter, explained: “Just helping her with her socialization skills, getting her out as much as possible. I think I’ve always encouraged her to be with other people.” Similarly, Liz suggested that she tried to involve her 21 year old daughter in “different community things and sports” and “tried to encourage her to do things with people.” Margaret recalled that her daughter “always had a close group of friends. I think over the years, I think I’ve helped her navigate that; that it’s okay to put yourself out

there.” For Jane’s 15 year old daughter, becoming involved with AboutFace was critical for fostering her social skills. She stated: “It was probably the best decision...once we did that, that was a real positive interaction. Making that step...and pushing the idea of going to camp and going to the social events.”

Amber, who is 17, recognized her mother’s involvement, stating: “She’s involved. Like a lot of my friends, their parents aren’t involved. She really understands because she knows what’s going on. She knows me...what I like, and the things I like to do. She knows my friends.”

Cheyenne, 22, also acknowledged her mother’s role, explaining: “She just checks up on me regularly with my friends...she knows who my friends are, and my friends know who she is. My mom would pick me up or drop me off... my mom would meet my friends.”

In some cases, mothers were instrumental in planning and organizing social events for their daughters to spend time with other children in an effort to ensure that these connections were maintained. For example, Ellen stated:

Really getting out there to plan play dates. Making sure if she got invited to anything...that she went. Really being the social planner...And then driving her there, and maybe, picking up her friends. So, I’m always the driver to encourage the social interaction, so that it doesn’t fall apart...I feel I have to get more involved than what I remember as a kid.

Lee also mentioned: “When they’re younger, you really try to promote play dates...going to birthday parties, having people over here. She was always invited to everything that was going on.” Alexa, who is 13, was appreciative of her mother always inviting her friends over “to make cookies and stuff.”

In some instances, this coordinating role was upheld and considered even when it impacted important family decisions, or meant a reconfiguration of the mother’s own social circle. Beth noted: “She comes with me to a lot of my things, too...I include her in my luncheons

or...you know, with my friends.” Maureen also recalled selecting private education for her daughter over public school because: “I picked a school where she could be with the same people from grade one through grade twelve.” Jane also maintained:

We didn’t really move her around a lot, and that was mostly because she had a group of friends that you know, in our eyes, we felt like they were almost her protectors...And all of these moms, we all became friends ourselves...we’ve sort of grown up all together.

Jordan, 21, reflected on her parents’ decision to move homes and its impact on her social life.

“They were always like, ‘If we’re going to move, it’s going to be in the same area.’”

**“*She taught me how*”:** *The educator.* The role of social educator was three-fold for mothers. First, mothers and daughters both recognized that mothers were proactive in educating daughters on others’ perceptions and opinions of facial difference, particularly the myths and stereotypes that society may hold. Many mothers involved their daughter in open conversation, often preparing them for the very real possibility of being marginalized in social situation. “She taught me how to act around people,” Delilah, 14, said, “how to talk nicely, how not to be rude, and how to treat people in a good way.” Ruth, also 14, noted that her mother have her advice “on what to do in certain situations”. Mothers also sought to indirectly reinforce their daughters’ sense of self with positive messages around the importance of personality and character, and de-emphasizing physical appearance. For Sabrina, 22, explained that her mother communicated “messages that it’s [her facial difference] not as important or as big a deal, and that people will like me for who I am.” Piper recalled her mother warning her “that some people will be mean and stuff, but you have to rise above it.” For Robin, this was done each morning as she got her 13 year old daughter ready for school. She stated:

I treated her facial difference as no big deal. I still put her hair up in pony tails. I didn’t try to conceal it. I didn’t imply in even the slightest way that it was something to be ashamed or embarrassed of.

Saoirse also commented:

I asked her before she started (at a new school), “Are you going to wear your hair up?...I think at some point, you should wear it up. You need to let them know it’s there.” And we had a big, long conversation about it, and on her second day at the new school, she wore her hair up. She put it out there for them.

However, many of these conversations arose in response to a situation or occurrence in which the daughters were exposed to negative social interactions, such as staring, isolation, rude comments and questions, and stereotyping. Marcia, the mother of a 22 year old daughter remembered:

When she noticed that people were staring at her, she asked me one time, “Mom, why are people staring at me? Why am I so different from other people?” I told her, “...Everyone is different. Nobody is the same. Don’t be ashamed of yourself.

Mothers also engaged their daughters in dialogues around their conditions in an effort to afford them the necessary skills to not only defend themselves in times that they feel marginalized, but to educate other people. The majority of the mother-daughter pairs recalled how mothers provided their daughters with age-appropriate language and quick summary phrases to explain their condition to unfamiliar people and curious children who may ask questions. Additionally, mothers also felt they had a hand in teaching their daughters various strategies to deal with the common experience of staring in a way that is both comfortable for them, and leaves the daughter with a sense of dignity. These include things like deflections, ignoring, and humor. “I remember answering questions in a very matter-of-fact way,” Sabrina remembered, “She must have sort of taught me that at some point.” Nessa, 15, also recalled her mother’s advice: “My mom always tries to tell me, ‘Don’t think about what they’re thinking.’ I always jump to conclusions and think they [people who stare] are thinking I’m ugly...she tries to tell me not to think that way and just ignore them.” Cheyanne, explained that her mother told her

“some ideas of how to deal with people who don’t like you...what to say if people make fun you”. Adina, the mother of a 13 year old noted:

We told her when she was a little kid, how to deal with these kinds of things. You know, say if people ask, to say, “It’s okay, this is just a birthmark,” because some people get scared when they see her. “Oh my God, what did you do? You fell? Or burned yourself?”

Robin also recalled:

When she was smaller, and people would stare, she would give them an angry frown. And I had to talk with her about that and say, “They’re just curious.” Now, as she’s gotten older, when little children stare or ask questions, she usually uses humour...when a little kindergarten child asked what happened to her ear, she said that it had fallen off because she didn’t eat her broccoli. We’re all just sort of ridiculous people, and use humour in all kinds of situations.

Margaret similarly reflected on the education of her daughter:

Questions are okay, but staring is not okay. And I always tried to prepare her that maybe she should have some kind of line to use so that if someone comes up to you or approaches you and has a question, how are you going to deal with it? So she came up with a one or two line response that if people asked her about her lip and why it looked different...that she would be able to respond when I wasn’t there.

In other instances, mothers were personally responsible for the education of others around their daughter’s facial difference; specifically, what it is and how it developed. Margaret, for example, remembered her response to individuals staring or asking questions of her daughters difference when she says, “I was the responder before she got to school.” In some cases, mothers and daughters recall the mother engaging in a conversation with a stranger in public who had perhaps asked a question, or had been staring at their daughter. Nessa joked that when her mother caught someone staring, she would “often go up and start a conversation with them and introduce me to them.” Other mothers adopted this education role more proactively and had exchanged information with individuals in an effort to make them aware of their child’s condition. This was particularly true in school settings. For example, Alison, who after her 13

year old daughter's surgery, went into her classroom to explain what had taken place: "She had a tube in her nose to shape her nostril, and I had to go into her school and talk to her kindergarten class before she came back so they wouldn't play with it." Cheyanne also recalled her mother going to speak to her kindergarten teacher: "She'd always be like, 'Yeah, that's my daughter. She has Cruzon's syndrome...she might feel socially isolated because of the way she looks.'" This was done most often in a school context, whereby mothers would go into meet and speak with the classroom teacher or her daughters' peers before introducing their daughter into the classroom. In either case, this edification was undertaken with the intention of helping others understand their daughters' difference, and therein breeding an environment of awareness, comfort and acceptance that is potentially less hurtful and more supportive of their child.

***"She's my mama bear": The defender.*** The last role that mothers play in the social realm is that of their daughter's defender. Daughters and mothers both recognize that in environments or interactions where the daughters were perhaps made to feel uncomfortable, stressed or overwhelmed, mothers felt the responsibility of confronting or diffusing the situation. Many mother-daughter pairs discussed how mothers were quick to come to their daughter's defense in school, where bullying and isolation may be occurring frequently, often involving not just the bully and their families, but school administration also. Adina, for instance, mentioned: "She's an easier target than a person without any differences, and people take advantage of that. We tried to tell her that if somebody is like that, what to do, and if it's very severe, to tell us." Ellen also reflected on her role in her daughter's school, saying: "I've developed a rapport with all the teachers to make sure I was on top of things...if I had to go in and complain about something, that they already knew who I was; that I was watching." Margaret similarly noted:

I was probably more protective of her. If there was ever anyone giving her a hard time, adults including children, I probably jumped in much quicker...So, at one

point when there was bullying and she knew that she couldn't handle it anymore, she came to me and I kind of addressed it with the parents of the identified child.

Jordan, remembered her mother's presence in her school:

My mom was on parent council and she was always in the school with our principal. If she walked into school...everyone knew who she was. One year in a class, I basically had a core group of five girls...I was in one class and all four of them were together in the opposite class, but she went to the principal and got me switched. She knew it was important to have a support group at school.

Nessa's memory was very similar to Jordan's: "Any time I have a problem in school, she goes running to the principal...if I'm too nervous to talk to a teacher, she's always there to do it for me." Cheyanne was also aware of her mother's methods: "She would bring me to school and be like, 'Go play with your friends'...and she would keep an eye out for me...if she saw something was wrong, then she would ask me about it and fix the situation."

Others made reference to instances of protecting daughters in social interactions with friends whom they felt were taking advantage of or hurting their daughters in some way, like Lee: "Something happened with her friends over the holidays, and I was like...I went off." Mothers also had a hand in defending daughters in their exchanges with strangers, particularly those in which staring, laughing, comments and questions are unyielding. Lee also recalled: "When we're out sometimes, in a mall, or at a food court, and they're staring, it's like, 'Really? What's wrong with you? Were you taught any rules? And I just want to go over there and smack their face.'" Robin also stated: "I think I'm a little more defensive...when she was a toddler, I occasionally caught people looking at her, and I would feel quite defensive about it and protective of her, and be angry with them." Some daughters, such as Avery and Amber, took to calling their mothers "Mama Bears" in response to their mothers' actions.

In addition to protecting their daughters, mothers specifically discussed defending their daughters, as well as their own actions and decisions regarding their care when they were

personally confronted by strangers with imposing, judgemental and insensitive questions or reactions. Lee experienced a situation like this on an outing with her daughter, “We would go to the park and hear, ‘Well, she has no ears.’ And I just think, ‘What’s wrong with you? You’re a mother. Why would you say that?’ For Alison, an interaction with another mother left her particularly defensive:

When she was little she had what was called a palatal appliance in her mouth which enabled her to eat, and she was very small. A mother told me that she thought it was barbaric that I would put that in my child’s mouth. I was quite defensive that I wasn’t harming my child, but that I was actually allowing her to eat.

Avery, who is 16, recalled how her mother responded to negative interactions in public:

I was in a restaurant, and there’s these two kids behind me, and they started talking about me, and their mom was like, ‘Shh, don’t be rude.’ And I remember being like, ‘Hey mom, can we leave?’ and she was totally cool with it.

**Teaching and learning to advocate for oneself: Navigating the medical system.** Due to the variability in the facial differences that each young woman was living with, the interactions with the medical system were unique to each mother-daughter pair; some daughters had undergone well over ten surgeries over the course of their lives, while others had undergone no surgical procedures, but rather participated in other medical interventions such as laser treatment and extensive dental work. While the interview questions around the medical system were general in nature, each of the mothers and daughters made reference to routine medical appointments and consultations, as well as preparation for and recovery from surgeries and other treatments. In addition to exchanges with doctors and surgeons, the women and girls recalled interactions with numerous clinicians, specialists, nurses, and administrative staff in their interviews.

***“She makes sure what I want is voiced”*: The advocate.** All of the mothers were highly involved in the medical aspect of their daughters’ lives. Many of the mothers mentioned the importance of asking questions of the medical system and various medical teams they came in contact with over time in an effort to understand the next steps in their daughters’ treatment as much as possible. As Margaret stated, “I wasn’t afraid to ask questions or force different issues.” Alison, too, joked that, “I never thought I’d be so aggressive in a doctor’s office wanting to get answers right away.” Jane also reflected on her experiences, noting:

I’m usually the one there that’s pushing for, ‘Okay, what is the next step? What are we going to do about this? I’m kind of being relentless in the fact that I want some answers and I want a plan. I push for that.

Alexa, acknowledged her mother’s presence in doctor’s offices: “It’s usually not me that has the questions. It’s usually my mom that has all the questions.” Amber also mentioned her mother’s tendency to ask questions: “...asking all the different questions, voicing it out there so like, you know that your options are; what to expect and all that stuff.” “She was always the one who was worried...she would be the question person...” Cheyanne recalled, ““What if this happens? What if this happens? What will go on? What should I do to prepare at home?’ She was more of the question-answer person.”

Many daughters discussed uncertainty or anxiety in medical consultations and appointments, which they felt inhibited their ability to speak to their concerns, or ask appropriate questions in the moment. Oftentimes, daughters would take up the issues, questions or concerns they had with future surgeries and treatments with their mothers prior to the appointments. As such, many of the mother-daughter pairs had devised a system in which the mothers would also ask questions on behalf of their daughters, or address specific concerns that their daughters had with the doctors, to ensure that their daughters were made equally aware of, and were

comfortable with the next phases of their treatments. “She is not speaking up as much or asking those questions,” Lee stated in regards to her daughter. “So I’ve said to her, ‘You have some questions. I’m okay to ask those.’” Alison, too, asked questions on behalf of her daughter: “If we’re at a cleft appointment or something, she’ll direct the question to me. She won’t ask the doctor. She’ll ask me directly so that I can ask them.” The dynamic between Susan and her daughter was quite similar:

Whenever we’ve had any appointment, I turn to her and say, ‘Do you have anything else?’ Usually she doesn’t. She’s very reluctant to speak up. It was the same thing...her and I communicating until I got where she was coming from and then I would repeat her questions to whoever it was that we needed to. I have to be the one that speaks up ask the question. She counts on that.

“[She] makes sure what I want is voiced,” said Amber of her mother, “Like, being able to make sure what I’m concerned about is covered. She speaks out on my needs and stuff.” Similarly, Avery commented: “For doctors, sometimes...I don’t really know how to start a conversation. I don’t know if I feel comfortable.” In many ways, mothers acted as their daughters’ voice within the system. In some cases, daughters felt they would assume a more passive role, and allow their mothers to navigate these appointments entirely as they looked on. In others, daughters felt they would gain confidence watching and hearing their mother interact with the doctors, and join the conversation when they felt ready and able to do so.

Additionally, as many of the daughters have transitioned into adolescence and young adulthood, they have begun to express a sense of agency in terms of medical decision-making, especially around continuing with surgeries and treatments for esthetic purposes. When these conflicts or debates began, some of the mothers mentioned how they have advocated for their daughters through defending and supporting their decisions to put non-functional surgeries on hold. Adina recalled some of the conflict that arose when her daughter decided to stop laser

treatment: “She did not want to go to anymore treatments, and we of course, as parents, wanted to continue...but we don’t continue.” Delilah appreciated her mother’s support when she was younger: “I didn’t want to do them [treatments] anymore. She would say it was my decision, and she wouldn’t try and stop me.” Robin and Saoirse similarly talked about their daughter’s agency in the medical system:

We’ve explained to her that there’s some things with her jaw and mouth that will need to be done because of dental health, and they’re not optional. There are other things for her appearance’s sake which are entirely up to her, and we really let her take the reins on that. [Robin]

There are some that are not an option. Like, if she needs another jaw distraction, she has to have it. She’s very adamant right now that she doesn’t want anymore (surgeries). But every now and then she comes out with, ‘You know, maybe I will.’ So, it’s a matter of letting her know we’re here, we listen, we’re open-minded, and whatever choices she makes, we’ll try to deal with it. [Saoirse]

Mothers also advocated for their daughters outside doctors’ offices and hospitals. Many dyads recognized the ways in which mothers would do research into the daughter’s facial difference to understand not only what it may entail, but what treatments may be in their future, and what new and well-received interventions are available. Alexa noticed that her mother “does a lot of research to see what can be done” and then “talks to the doctor about the research she’s been doing.” Delilah, too, suggested that her mom “researches it [her difference] because she likes to research things”. Robin even consulted an online forum to discuss her daughter’s future interactions with the medical system: “I went online to a chat group for people with similar facial differences and parents of them, and I asked when whether I should even have the surgeries.” Some mothers, like Jane, also took the initiative to organize all of the medical information pertaining to their daughters to keep track of important information overtime, and give all medical personnel up-to-date information. She kept a “binder than has just everything from dental, rheumatology...all the little bits and pieces”. Nessa talks about her mother’s role in

taking her to her appointments, and how she's "taken it upon herself to remember everything and always know what's going on...she's definitely the one who takes care of everything, and organizes everything." The majority of them discussed being proactive in planning ahead, and staying on top of all appointments and consultations to ensure that their daughters do not fall through the cracks within the system. For instance, Lee described how she likes to have all of her "ducks in a row" when it comes to medical appointments, stating that she is "the one that keeps it all in check, phones about the follow ups...just keeping it all together." This was especially important for those who had previously been subject to neglect by the system, like Liz:

When she was little, I guess she missed one of her annual follow-ups...and I guess it was that that sort of kept me calling, kept me inquiring...saying 'What's next?' or 'We want a game plan. We want to know what steps are next and what's going on.' We knew that if you don't follow up, you can slip through the cracks. It was sort of an eye-opener that made us more aware.

In a similar fashion, mothers also recounted their advocacy to ensure their daughters received the best medical care available. Many mothers discussed lobbying for more support outside of the hospital, especially when their daughters were young; switching doctors or medical teams when they felt it was necessary or in their daughter's best interest; and voicing their opinions, suggestions and recommendations to medical teams, and ensuring that concerns or issues were addressed in a timely fashion. Beth remembered the struggle to find a doctor who would diagnose her daughter:

It's been so frustrating because she wasn't diagnosed until she was three, and I knew all along she had something, I just didn't know what she had. Going to my family doctor, going to a pediatrician, he said nothing was wrong. I took her for a hearing test...I've really had to beg and plead with the medical system just to listen.

Jane had a very similar experience when her family struggled to receive an accurate diagnosis for her daughter:

When she (daughter) was five or six years old, we started noticing a change in her jaw. We talked to our GP about it, and he basically said it was just a dental problem. But over the years, your instincts...we kept thinking, 'This doesn't seem real.' After four dentists, we ended up at Sick Kids Dentistry. She was nine.

Ellen also recalled her struggle to ensure everyone was on the same page in regards to her daughter's care: "We've had extra appointments with the health care providers when we went into this last procedure because between the medical staff, there was some miscommunication." Robin likewise reflected on "a couple of negative experiences with doctors that were less than satisfactory" and how she "didn't hesitate to ask the pediatrician to recommend somebody new." Saoirse came her step-daughter's defense when she felt medical personnel were not respecting the family's decision during the recovery phase, becoming "very, very firm" with the nurse. Margarget too, recalled that there were "a lot of times that there were questions and I had to put my foot down, or I was in the hospital with her and really needed to speak up to make sure that she (her daughter) was okay."

Ruth asserted that her step-mother "got mad" at the nurses after one surgery: "I had one nurse who gave me way too much IV fluid so I was like, swelling up...and she kind of yelled at them about that." Jordan also recognized that her mother was equally strong in advocating for her care:

If there's a problem, it's like, 'Okay, let's call. Let's get this fixed and call right away.'...No matter what, if there was something with anything with a doctor, dental, anything medical, my mom was always like, '...We'll take care of it.' She really fights for it. And she still does it... No matter what I needed, even if it was just something that came loose, it was like, 'Let's do that right now. We're not waiting for the doctor.'

What is perhaps the most interesting facet of the advocacy role, is the recognition that the mother assumes this role to ensure and prepare the daughter to advocate for herself in the future. For many of the pairs, there is explicit discussion of modelling this proactivity and attention so

that daughters can learn the importance of and strategies for securing comfortable and effective medical care. Ellen mentioned: “I’m teaching her how to advocate for herself, so if I’m not there, she knows what questions to ask, and now to let anyone back her into a corner.” In discussing how she always asks questions at her daughter’s appointments, Alison stated, “She’s got to get better at it, because I’m not going to be at every single one the older she gets.” Jane also noted: “I think it’s bridging, where she can start advocating for herself. She just had an appointment this week, and she actually expressed frustration with the appointment she had with another doctor...I was very happy for her.” “I’ve watched her do it,” Delilah said, “So, I kind of get how to talk to doctors.” Sabrina also recalled:

I remember a couple times, going in for consults for surgeries or whatever, and they would be talking and I wouldn’t understand all of the medical jargon...and then they asked me to sign the consent form...and I was like, ‘I’m not signing that until you explain to me what’s happening.’...And my mom was pretty impressed with that.

***“I don’t need a nurse...I have my mom”:* Emotional and physical support.** Somewhat related to their role as their daughters’ advocates, every mother was also very active in the medical aspect of their daughters lives, accompanying their daughters to many, if not all, of their appointments and consultations; even when the daughter had transitioned into emerging adulthood, and is able to transport themselves to and from appointments. It is important to note however, that this role is welcomed and appreciated by the daughters, regardless of their age. In taking on such an active role, mothers become extremely familiar with the doctors, nurses, specialists, clinicians, and other medical staff that their girls interact with on a regular basis. Liz is so involved that she said, “The secretaries currently know me by first name because I’m a pain in the ass.”

Mothers and daughters alike acknowledged that mothers are also highly involved before and after surgical procedures and treatments. Many of the daughters recalled how mothers were able to discuss upcoming appointments and procedures with them in a way that informed them of what was going to take place in age-appropriate language, while controlling and alleviating some of their anxieties. As Saoirse said, “I always like to make sure she is informed.” In one specific instance, Adina, who, like her daughter, Delilah, is living with a port-wine stain, allowed the doctors to test a laser on her own skin to make Delilah more comfortable undergoing the procedure herself: “I said, ‘Well, okay, if you don’t want to try it, I’m going to let them try it...to do some treatment on my skin and you will see how I am going to look, and then you can decide.’” Cheyanne recalled: “From the start, she told me what I was going in for. She would explain the situation...what will happen, the process of it, and the recovery...in non-medical terms. She would remind me that it was coming.” Margaret, even went as far as to go against hospital policy to ensure her daughter understood what was to be expected:

Their approach to children that are having surgery...was not to tell the child they were having surgery until the day before, and I think it was said that morning so as not to alarm them. I never believed that...We always told her about the surgery. We would talk about it months in advance...so she knew that it was coming.

Many of the mothers also took time off work to be with their daughters as they recovered from surgeries or spent time in hospitals, and in many ways, filled the role of a nurse during this time frame; taking on routine maintenance of wounds and hygiene, and encouraging their daughters to follow doctor’s instructions and exercises to promote healing. Marcia remembered: “When she was in the hospital for two months, I never left her there, not even a single day. Sometimes they said, ‘Are you a nurse?’ And I said, ‘No.’ I did all the suctioning; I did everything.” Ellen also stated:

She's used to having me there for all the pre-ops and then being there at the hospital as well...helping her bathe and stuff after surgery...I'm there helping her, getting up every couple of minutes to help her with her mouth, her suctioning, whatever it is...the bathroom.

And Robin recalled:

Sitting in the waiting rooms, waiting for the surgeries to happen, in the recovery room...helping her cope with discomfort. After her very first surgery, they took out rib cartilage to make part of an ear for her, and afterwards...she had to do breathing exercises and she didn't want to because they were painful...I tried to take the approach of, 'I know this is really hard, but you can do it.'

Daughters recognized their mother's presence in the preparation and recovery as well. Amber stated: "She takes me there and she stays with me." Ruth noted: "She likes to give me whatever I may desire at that point. She likes to be there." "My mom is kind of like a nurse," Jordan explained, "I don't need a nurse because I have my mom. She's really good with everything...she does like, anything and everything that I need." Cheyanne also commented:

My mom has been fabulous from start to end...She's always been there. She's always ensured everything is okay the day of surgery. She'd basically just be there to hold my hand if I needed it...she would always walk me to the operating room...she would take work off for a week, or however long she needed to take work off.

**Assuming the role of, and appreciating, the messenger: Navigating the family.** The mothers and daughters who participated in the study belonged to a diverse set of family systems; some discussed their very large, close-knit extended families that included uncles, aunts and cousins; some made reference to grandparents, or close family friends; while others focused solely on their nuclear families. It was easier for the mothers to reflect upon the ways in which they helped family members adjust to or cope with their daughter being born with or acquiring a facial difference. The majority of the daughters were unclear as to how their mother initially navigated the family system because many were infants at the time. Regardless of whom the

mothers and daughters made reference to however, all of the mothers were found to play the role of the liaison in their interactions with their family unit.

***“Keeping everyone informed”*: The liaison.** Mothers and daughters alike recognized that the mothers were very open with all members of their family around their daughters’ difference and what it meant for her and the family moving forward. The dyads acknowledged that mothers were also responsible for keeping their family members in the loop regarding upcoming surgeries and treatments that their daughter would undergo. Many mothers felt that they never hid their daughters from their family, but instead, attempted to foster acceptance within the family unit through their honesty.

For instance, Beth mentioned, “I’ve always talked openly with all of our family members, and I’ve never hidden anything. I keep everyone informed...whether we’re going through surgeries or not.” Alison recalled how she “tried to explain to them as best I could” what lay ahead. “At first, they (extended family) were very frightened and they didn’t know what was going on...we explained...that everything was going to be fine, and that she is a healthy baby.” Robin and also noted issues with their daughter’s paternal grandparents: “Early on, they thought she was more fragile than she was. They treated her like she was an invalid almost. The thing I tried to do was just reassure them that she was fine; she is healthy, she is strong.” Liz and Margaret similarly recalled how they sought to be “as open with everybody as possible”, never hiding anything or avoiding the topic with family. Liz stated, “We talked about everything,” and Margaret noted, “We didn’t close it off...there was no isolating or not connecting.” Even in instances that the daughters could not highlight specific ways in which mothers were able to achieve this, daughters recognized that members of her family were always accepting and well-informed, and that this must have come from their mothers.

Amber was aware that when she was preparing for surgery, her mother “kind of helped them [extended family] understand what it was...explain what work I’m having done, or why.” Delilah’s mother also explained her procedures to her family; “what it is, and what it does or doesn’t do.” Both Jordan and Nessa recognized how their mother acted as the “middle-man” with their siblings, too. Jordan said: “Somehow he [her brother] always finds out what’s going on with me, so I’m sure she talks to him about what’s going on.” Nessa explained: “My mom talks to my sister a bit...and my family. She always tries to talk to them and make them understand why I feel the way I do about my face...she’s always like the messenger.” Finally, Cheyanne jested about the amount of liaising her mother did with her family: “Usually it’s my mom who talks her mouth off...whenever we’re meeting a new family member, my mom...would like take the reins and explain to them what I have from start to finish.”

In families that had other children, mothers and daughters were equally sensitive to the needs of siblings, and many pairs discussed how mothers tried to incorporate siblings into their daughters’ life; bringing them along to medical appointments or the hospital after surgeries, having discussions with them regarding the daughters’ difference, and answering whatever questions that may have arisen. Saoirse, who had a son close in age to her daughter, recalled that he was “very sad when she had her first surgery because she had this bandage on her head and she was in pain.” She “explained everything that happened with the surgery” and “even pointed out the various places where when the bandage came off, he would be able to see the scars.” Jane, who had another younger daughter discussed how she’s “helped her to be aware and be okay...to maybe get frustrated or feel angry.” Sometimes, Jane felt she was “the referee going back and forth between the two, explaining how the other is feeling.” Moreover, some mothers and daughters recalled how mothers aimed to ensure that some of her time was spent with her other children, in an effort to strike a balance within the family unit and avoid anyone feeling

neglected. Ellen, for instance, started having “mommy-day, daddy-day things” so she could spend time with her son, and her husband could spend time with her daughter. Alexa, too, remembered how her mother would “make a day” with her brothers, “to make sure they didn’t feel so left out.”

Naturally, this role depended heavily on the relationship that both the mother, and nuclear family unit, had with the members of the extended family. In cases where strain or tension did exist between relations, the mother’s liaising was done either to a lesser degree, or not at all, in an effort to protect themselves, their daughters, and their families.

**Attending to media images and interactions.** Despite not being included in the interview protocol with a set of specific questions, the media was a system that was addressed throughout many of the interviews with mothers. While there exists many forms of media, those that were mentioned most frequently within the interviews were Facebook, mobile networking, magazines and print media, television and movies, and news outlets.

*“I know how hard it is...the digital age for girls”: The gatekeeper.* Daughters interacted with each of these sources in unique ways, however, mothers discussed regulating what types of media their daughters engaged with, and in what ways. Some mothers, like Beth, limited their daughters’ access to Facebook: “I’ve held her back in social media. She will use my Facebook account...but she doesn’t have her own.” For those women who assumed this role however, there was discussion around these precautions and limitations being in place for the daughters’ benefit; specifically, so mothers could be made aware of, and protect the daughter from harmful or hurtful interactions like cyberbullying. For instance, Lee stated:

She didn’t actually have Facebook until close to the end of grade eight. I’m really kind of protective about that aspect because you hear so much with mental health

issues, with online bullying...I would just be devastated if I knew there was anything circulating that way.

Alison also made reference to her fears around Facebook, and stated: "I'm nervous about the road ahead for her. I know how hard it is in the digital age for girls in high school...things on the computer and on Facebook...all this bullying."

Many of the mothers would engage their daughters in open discussions regarding models and actresses depicted in the media, with particular emphasis on the issues of bodies and beauty. Some mothers tried to counter the messages that they found prevalent in the media regarding beauty ideals and perfectionism with critiques of photo-shop and other editing procedures, while other mothers chose to de-emphasize the importance of physical appearance, and instead focus on the significance of character and redefining beauty. With regard to her daughter's idolizing celebrities, Ellen commented: "I always emphasize inner beauty. I like the stars that had good personalities and not just because they're pretty. They're always photo-shopped. You can photo-shop anything." Jane did the same with her daughter: "When we go into the magazines and she's looking at magazines...I've always been behind her saying, 'Oh yeah? Well look at this YouTube video. See how it's not perfect?'" Similarly, Robin tried to mediate her daughter's use of magazines:

She's not into it too much...I may have actively discouraged her because of the pressure to have a certain look and be a certain way. I think it's really unhealthy, especially for a young woman who is just figuring out who she is. I wouldn't want her to look at pictures of women in magazines and think, 'Why don't I look like that?'

**Maternal tensions and strains.** As discussed above, the roles that mothers play in their daughters' interactions with various systems are often seen as necessary. However, these roles are not without their own challenges. While many mothers suggested that these roles were vital to their daughter's care and an essential part of their own lives, many of the mothers similarly

noted how complex and difficult some of these roles and responsibilities can be, especially within the context of their relationships with their daughters. For instance, a number of mothers discussed how tiring adopting the role of their daughter's social co-ordinator can be, or mentioned the complexities associated with being the family liaison. "I don't get a break," Beth said. Ellen similarly stated: "It's the breathing space. She's so used to me being close...it gets a little tiring having to worry about somebody else's social life all the time." Other mothers noted the difficulties in being their daughters' advocate, physical and emotional support in the medical system. Maureen suggested that "I kind of indicated to her that maybe she would want plastic surgery on her nose...by bringing it up, I think I made her feel like there was something even more wrong with her." "Maybe I offered too much information as a medical professional," Margaret admitted. "That was overwhelming to her." Ellen commented:

You don't know how much to push in the direction of getting something done or not getting it done. When do I push? When do I back off? I don't want to be an overbearing parent. I don't want to push her into anything she doesn't want. But at the same time, I want to be sure, because I don't want her to make a decision now that later on, she'll regret.

There was particular emphasis on the internal struggle of wanting to care for their daughters and put them at ease, all the while respecting their decisions about their own bodies, avoiding sharing too much information and causing more anxiety, or being too supportive and "coddling" their girls. Lee reflected that "it's the intensity sometimes. I feel it's a challenge because I want to get in there and make it all okay right away, and realizing that you can't do that all the time." Likewise, Maureen noted that she may have been "too protective" of her daughter, "not letting her out there to do things she needed to do." Margaret also commented that "You want to make things better and fix things for them, and sometimes you can't fix it; they have to kind of find a way to fix it themselves. I maybe could have done that earlier...let go a little more."

**Daughters' tensions and strains.** Daughters, too, are subject to their own stresses stemming from the roles their mothers play in the various interactions in the systems they contend with. For example, a number of daughters mentioned how uncomfortable they felt when their mothers adopted the role of educator and defender in the social realm. Many felt as though they were old enough to navigate social interactions on their own and disliked the sometimes additional attention their mothers' actions warranted. "I can fight my own battles," Avery mentioned, "But I think that's also really sweet that she's kind of overprotective." Sabrina felt like she was "too dependent" on her mother, and that she didn't have "enough of her own life". Jordan explained:

Sometimes when I talk to strangers, I don't know how to talk or how to start because my mom always talked for me. I know that she was just trying to protect me...but at the same time, you grow up eventually and you need to do it yourself.

Cheyenne cited:

Sometimes what she said didn't really help much...sometimes she'd be like, 'Yeah, just tell them it's nothing, it's fine, just ignore them.' ...it wouldn't really help the situation...Or keeping tabs...I didn't really feel that comfortable. I felt like I was a kid with needs or something, which I'm not.

In a similar sense, the majority of daughters felt that, while they were appreciative of their mothers advocacy and support within the medical system, that they remained uncertain as to what questions should be asked of doctors and how, given their inexperience with handling these scenarios personally. "She could have explained it a bit more," Delilah noted, "And not just brought me to watch her." "She's been my advocate the whole time, and now I have to advocate for myself, and I can't as easily as I thought," Jordan reflected. Some daughters also stated that despite their mothers best efforts, conversations that were initiated around upcoming appointments, consultations and surgeries caused more anxiety regarding the upcoming procedure. Ruth thought:

She can...without even meaning to sometimes, she says the worst scenario, and then she'll be like, 'Well, that's not going to happen,' right after saying it. And you are just kind of like, 'Well, I didn't even think about that until you said it.' ...It makes you more nervous to talk about it too much.

Nessa also commented: "She doesn't understand how difficult it is for me...I don't like getting very into the medical part of it...I don't like the whole planning and documenting everything, and she gets really frustrated with me."

### **Mothers' Role in Daughters' Adolescence and Becoming Women**

Given the complexities inherent with the adolescent years and the various transitions that young girls encounter over the course of their youth, the second objective of the project was to understand the role of mothers in their daughters' adolescence. Interview questions highlighted specific issues such as: identity, femininity, relationships, sexuality, and body image, but mothers and daughters also made reference to other realms such as employment, and extra-curricular activities. While the interview questions focused on the role of mothers in their daughters' adolescent development and transitions, many of the themes that arose in the narratives centered on the ways that mothers helped their daughters navigate the processes of becoming women. The two themes that emerged from the data concerned the way in which mothers and daughters conferred about adolescence, its associated transitions, and the aforementioned issues; as well as the content of the lessons and messages that mothers imparted to their daughters.

**"She looks to me": Modelling, teaching, talking and sharing.** Many of the mother-daughter pairs mentioned that they felt the mother had served as a role model for the daughters, influencing their daughter's identity through exemplifying specific characteristics on a regular basis. By the same token, many of the dyads discussed that the daughter's sense of femininity and body image were shaped by looking to their mothers. This was particularly true around

things such as the use of make-up, fashion, exercising, and healthy eating. Many of the dyads also made reference to the ways in which the relationship modeled between the mother and her husband motivated the daughters to seek out loving, committed, and stable partners and relationships. For instance, Lee said:

I'd like to think that she sort of looks to me as a person being able to cope. I like to think that I represent to her somebody who's like 'Oh, this is not a great situation, but it is what it is. Let's move forward.' I'm not...like high maintenance in terms of my clothes and make up....As a woman, think I present a strong, independent thinker.

Saoirse also mentioned: "She's learned from me that girls don't have to fit into this tiny little pink category. She's learned that they can like sports and they can like cars, and they can be fanatical about music." Maureen also commented: "I don't try to make myself look beautiful, you know? I've never really been...I don't wear make-up or whatever." Margaret explained: "I always worked, and...she liked the idea that I worked, that I had a job, that I was a professional that really sort of had my own thoughts." Finally, Jane reflected:

That's the kind of role model I've been, where I've changed my life to become more positive...maybe she sees that you can come out of that dark place, and there is a good place you can come to. I've been married to my husband for sixteen years, very happily married...I'm hoping that's what she sees; that there is goodness.

Avery mentioned that her mom modelled some of the "feminist views" on the power of women: "I think she believes that...that women are just as good and maybe even better than men...I think her views on that kind of influenced me." Amber agreed when she said:

My mom works in a medical field, which is pretty significant and stuff...I admire her education and her skill. I think that it's empowering that she has a career that's her own, and that she has her own hobbies and her own interests...I think that's kind of taught me to be an independent woman.

Not all modelling from mothers was interpreted positively by the daughters, however. Sabrina, for instance, noted that her mother was “really critical of herself...about her weight and her eating” and that she felt it hadn’t “helped her a lot”.

Moreover, every mother-daughter dyad included within the study made reference to conversations that took place between them, addressing a variety of adolescent issues. For some of the pairs, these dialogues took place in a very explicit manner, where mothers clearly and directly addressed certain topics with their girls. Adina explained: “We try to talk to her many, many times...about all the kinds of relationships she will have; with her friends, with boys... We try to talk to her about drugs...about sex.” Marcia also recalls numerous daily conversations with her daughter: “We usually talk when we are eating dinner or at the table. We always talk...she’s always open.”

For others, subjects were broached in a more indirect or implicit manner, often conferring about situations taking place in the life of the daughter’s peers, or situations that their daughters witness in the media. Robin, for instance, recalled a number of these indirect conversations: “We’ll see a young woman her age walking down the street looking like a girl of twenty going clubbing. And I’ll ask her, ‘Well, what do you think about how she looks?’ And we’ll open a dialogue and discuss it.” Alison also recalled teaching a young girl with anorexia, and addressing it with her daughter: “She asked me what was the matter with her and why she was so sickly looking. So, I explained that it was a disease...that it’s very dangerous to do that and play with your body that way.” Nessa noted:

If there is anything on the news, or anything that she hears about...anything on the news that’s serious, she kind of makes me watch it and brings it to my attention and asks me what I think about this...she tries to see what I’m thinking and point me towards a better direction.

Additionally, the majority of mothers used stories of their own adolescence and teenage years as an effective means of speaking about a variety of issues with their daughters, sharing their own experiences, and teaching their daughters lessons about growing up and becoming a woman. Ellen helped foster her daughter's involvement in school by sharing her story: "I did keep telling her that I got involved in various activities and how that made my high school rewarding...when things come up and I can think of something...then I say, 'Yeah, I went through that.'" Beth also recalled her time in school, stating: "I've told her about when, going through high school, how mean the girls could be sometimes...just to prepare her so she knows." Saoirse also shared some more difficult stories with her daughter: "All my experiences with negative relationships. I really want her to get that...that she is not there to be the toy, or the punching bag of a man." Amber recalled her mother talking about her own childhood: "When she was a teenager, her connection with her parents wasn't really good, so she wants me to have all the things she didn't...she wants me to feel positive and safe and supported." "She tells me about friends and boy troubles that she had when she was younger," Delilah said, "And sometimes, I kind of take it and think about it to see if that can help in in any way." Finally, Sabrina, too, noted:

She does share a lot, I guess, about her upbringing, and just that she also felt left out...that she was kind of a wall-flower person too...I guess it kind of made me feel like it was okay to be more introverted and that it was...that she turned out okay I think...it kind of helped me to see that feeling awkward was, I guess, normal or like, okay.

**“Be who you are”:** **Communicating validation and empowerment.** Overall, there was a high degree of consistency within the content of the conversations had in the aforementioned conversations between mothers and daughters. Within all of the dyads, one of the messages communicated by the mothers centered around validation. Many mothers made a concerted effort to help their daughters feel like their adolescent experiences were akin to not only their

own growing up, but also the experiences of many other teenage girls. Some mothers placed particular emphasis on issues of body, gender and identity, communicating that their daughters needn't be ashamed of who they are, what they looked like, or how they carried themselves.

Amber appreciated that her mother communicated “not to worry too much about what other people think...not to let it stop you from doing what you want to do and being who you are.” Avery, too, commented that her mother taught her to be a proud and independent woman: “This is who you are, and yeah, you're a girl, but that doesn't change anything...if I say something negative out loud, she'll compliment me, which makes me feel a little better.” “She tells me that I'm perfect and fine,” Delilah said, “And I guess that sort of helps, like, I don't feel bad about my body. I know that there's nothing wrong.” Ruth mentioned that “all along the way” her mother told her that “no matter what body you end up having, it's okay, it's what's on the inside that counts.” Jordan also recalled that her mother “always said, ‘You're beautiful...it's not about what you look like and what you sound like, but it's about who you are and your personality.’”

Adina noted that she always told her daughter “that being a little different sometimes is a good thing” because “you stand out from the crowd and you're not just one of them.” Saoirse stated that she has “tried really hard to make her understand that she's her own person...no matter what her body looks like, it's hers.” Marcia, too, validated her daughter by always telling her, “‘You are a special girl.’” She continued to mention that when she recognized her daughter was feeling down, she would “always give her a positive answer and build her up so that she will not feel inferior with other people.” Maureen hoped that she had conveyed to her daughter that she's “not the only one who has these feelings [of insecurity].” Robin sought to help her daughter be comfortable with her body:

We tried to convey to her that it's alright. Sexuality isn't something to be afraid of; it isn't something unnatural... We tried to help her develop the sense that her body and her body image... is something that is natural; it's something that is healthy, something to be proud of. But at the same time... it's not something to be careless with. She needs to understand that her body is valuable because it's part of her.

This theme of validation served to support the young girls in being comfortable with themselves, and normalizing their experiences.

Additionally, mothers often used their relationship and conversations with their daughters as a means of encouragement and empowerment. The majority of mothers felt they supported their daughters in expressing not only their identity, but femininity and sexuality, through their unique sense of style. Lee suggested that she tried to take her daughter's lead and encouraged "trying to express yourself individually, within reason". Ellen was a great example of this when she detailed:

I've tried to encourage her to bring out her own personality... taking her cues as to what she wants to do with her hair. She wants make-up, let her have make-up. I'm encouraging her instead of stopping her... I'm a bit more open. We have limits, but at the same time, allowing her to express herself with her clothing. I encourage her to go out and experiment with her clothes.

Amber discussed how her mother "wear stuff and feel good in what she wears", and Sabrina commented that her mother "supported and encouraged" her when she wanted to "try out make-up and stuff like dying her hair".

Many mothers promoted their daughters' pursuit of education, not only by aiding with homework, but by frequently reinforcing their intellectual abilities, and encouraging them to continue in school. Sabrina said her mother gave her more freedom to "pursue stuff" she was interested in in school: "I wanted to move away for university even though I was quite attached to her and to home... but she let me try that anyways." Cheyanne also recalled: "She's supported me academic-wise... 'How are you doing in school? How are your grades? Do you need help

with your essays or studying?’ She’s always been on top of me academically...she’s helped me to study.” “I’ve supported her in her educational goals,” Maureen commented. Marcia also noted that she supported her daughter “in her studies and whatever problems she encountered with school.” Liz even celebrated her daughter’s entrance into graduate school during her interview: “I’m not trying to brag...she’s smart. She’s an A-plus student. She just found out...she got into her post-grad program...I said, ‘Did you have any doubts, really?’ Like, an A-minus was her lowest mark the last three years.” Like Liz, a number of mothers were also extremely supportive of their daughters’ future aspirations, including career goals.

Moreover, mothers encouraged participation in various extra-curricular activities that were of interest to their daughters, and supported their involvement in the activities a variety of ways. Amber appreciated that her mother “made her aware that she had opportunities available to her” and “gave her the opportunity to try a lot of things...skating lessons and swimming lessons and whatever.” Jordan said:

She’s pretty much supported me in everything...I play a lot of sports, so that was a big, defining feature of my life, so anything I wanted to do, it was like, ‘Go for it! You can do it!’ I think that’s made me more confident...whenever I wanted to do something, they were like, ‘Yes! Do it! That’s awesome!’

Cheyenne also commented:

Ever since I was in grade six...I wanted to get into music, and I wanted to do violin...she understood that I really wanted to do this, so she was all in...that was a big thing for me. Another thing I could think of is involvement in high school...she was always my support behind all that. She’s always been supportive of all my extra-curricular activities...In my involvement with student council, my mom was all for it...she would help me out with my posters...

Beth encouraged her daughter to “try what she’s wanted” and introduced her to activities like “skiing and music and outlets that she can turn to, to keep herself entertained and enlightened”. Alison noted: “I’ve encouraged her to follow her dreams. Like, to keep up with

what she wants to do. She's a very good artist... she can go to a school for the arts." Liz recalled that "hockey was the biggest part" of her daughter's life, and that she "tried to support her" as much as she could. Ellen also stated she was instrumental in getting her daughter "exposed to a lot of outside activities; showing her not to be afraid of trying new things, and that it's okay to fail...go and check something out because you may have discovered a new interest; a new way of thinking."

Many mothers also sought to boost their girls' sense of self in relationships; bolstering their daughters' identities as strong, independent, and capable women, who deserve partners that treat them with respect and dignity. "I don't want her to settle for the first guy that comes around," Beth asserted. Robin said the same: "I've talked with her about how she needs to select partners who will treat her with respect and who will care about her... We've said that any boy who's really worried about your facial difference isn't worth your time anyhow." "I've always instilled in her that we are strong women and we can do anything," Alison claimed. "Because of her," Amber explained, "I want someone who will treat me well...it should be about what I want...to be with someone who is going to accept me and treat me well." "My mom grew up believing that women always had a strong place in the world," Nessa discussed, "and that men couldn't get on without women and that women could do any job that men could do...she always tells me to go for it even if it's something a guy would do." She continued to say: "She's always like, 'I don't care if you love the guy...if he's rude or mean in anyway, he will be leaving this house.' ...She wants the best for me."

**"There's just so many layers": Undoing intersection.** As stated in the theoretical frameworks section above, intersectionality is a critical component of the daughters' identities: they exist not only as a developing young woman, but as a young woman living with a facial

difference. As such, many of the daughters that participated within the study felt that they were unable to separate or consider the issues of adolescence and becoming women without considering the influence of facial difference on their experiences. What is interesting however, is that a number of the mothers made reference to their attempts at disentangling some of the issues their daughters face throughout their development from their facial difference.

Specifically, these mothers discussed how they felt it was important to tease apart the complex layers of their daughters' experiences as a developing young woman, and identify what issues are perhaps related to the challenges associated with growing up and coming into womanhood, and what issues stem solely from having a facial difference. Jane, for example explained:

Unfortunately, when you have a child with a facial difference, or maybe a sick child...there's just so many layers and it gets so confusing because you associate so many different things and you're constantly second guessing...It's like, 'Are you feeling this way because of this?' or 'Is this happening to you because of this?'

Margaret agreed by saying:

A big piece of it for us was, what piece was just adolescence, and what piece is the craniofacial piece layering on other problems or other issues? It's easy to blame a lot of it I think on the cleft-lip and palate, and I think in a lot of moments, if they take the time to think it through, a lot of it didn't have to do with it...I've always tried with her to...help her recognize what she's really talking about...she did bring it back around to her cleft-lip, when really, what she was talking about didn't have anything to do with a cleft-lip.

Mothers were quite sensitive to the intricacy with which these two facets were intertwined, but felt that this separation was important for the daughters to gain perspective or insight into their own opinions and emotions, thus making them better able to perform this deconstruction on their own, and withstand being overwhelmed by their entanglement during the process of becoming women.

However, a number of girls had difficulty separating these developmental experiences from those associated with their facial difference. When asked about their adolescent experiences, a number of girls, like Jordan, Sabrina, Nessa and Cheyanne, asked if the question meant “in general” or “with a facial difference”, and then struggled to isolate the two in their responses. Avery articulated her thoughts around the centrality of intersecting identities in her life when she said:

It’s hard to separate it cause like, I don’t think I would have to deal with so much if I didn’t have my facial difference...it’s always there. I wake up in the morning, I put on my hearing aid...I feel like my facial difference does put barriers in stuff, so I’m not sure how to be like...’just in general’.

**“She loves me and it doesn’t really matter”:** **Reframing and resisting.** Altogether, these three aforementioned themes serve as a unique form of armour or hardiness for the daughters and mothers alike, protecting them in the face of marginalization and stigmatization. In having open discussions with their daughters, validating and empowering them in the process, the majority of mothers sought to reframe some of the challenges their daughters face in becoming women, including body image, gender, identity, relationships and sexuality, and help them resist the erosion of self, imparted by the intersections of developing femaleness and physical difference.

Many of the daughters confirmed that their mothers’ lessons helped them to feel confident in who they are as individuals and young women. Daughters like Sabrina, Piper, and Alexa had difficult times identifying ways in which their mothers were perhaps not helpful in helping steer them through various systems and adolescence. Avery noted: “I think she loves me for who I am, which is really nice. It makes me feel so good...I really feel like there’s a safe place to land with her, which is really nice...it gives me more confidence.” Amber also claimed: “I always feel safe and accepted...she loves me and it doesn’t really matter...you feel accepted

and you feel like you belong. It's a good feeling just to feel safe and secure." Jordan reflected that superficiality is "not a big deal for her" and that stemmed from her interactions with her mother. She said, "It's being confident in who you are and being proud of who you are and not what people want you to be." Cheyanne also appreciated:

...the fact that she treats me like an normal kid...she tells me that I shine in other places, or she brings out the best in me in other perspectives...I really appreciate that, and I'm really grateful that she can do that for me...my mom would always reinforce the fact that I am beautiful in my own skin, and that a facial difference means nothing...I guess that empowers me to see how I shine in other perspectives, or bring out my best in other lights, and that my facial difference plays no part in what I do.

Similarly, despite feeling uncertain at times, mothers considered these discussions their best-effort in supporting their girls through navigating their adolescence; a number of mothers felt that they validated their job as a good mother, despite what other people, and society as a whole, thought or said. Marcia said: "I gave her all of the support she needs...I am very proud to say that I think I did my best to help her grow up." Mothers like Saoirse, Maureen, and Liz found it difficult to highlight ways in which they were not helpful in guiding their daughters through systems and adolescence. "I'd like to think I've supported her in every way. I cannot think of anything that I did that did not support her. I hope there is nothing," Adina suggested. "I tried so hard," Jane similarly conveyed. Lee reflected on her journey, and said:

You get better as you get older...you get better at weeding it out. You know, seeing someone who truly cares compared to someone who is just being nosey. It took me a little while to go, 'Oh gosh, I don't actually have to explain myself. I have a right to say, you know, it's really none of your business.'

Robin also shared:

A lot of other people that I meet both in the medical profession and just sort of generally, they go out of their way to compliment me on how accepting I am of my daughter...as if that's not what should be expected. And that's always taken me aback, because...I mean, the moment they put her in my arms...I loved her

instantly. Her facial difference wasn't an issue, but it seemed to be expected that it would be, and people have marvelled that it wasn't.

As such, these conversations and lessons serve as a unique sense of armour for the mothers as well.

### **Unique Contribution of Facial Difference**

Given the theoretical foundations of the project, one of the study's objectives was to understand and highlight what facial difference can contribute to both the lives of mothers and daughters independently, but also what it can contribute to the mother-daughter relationship as a whole. Overall, there was some discussion of the ways in which facial difference has made the daughters more self-conscious and anxious. A number of daughters noted how they perhaps compare themselves to others more, or tend to withdraw from social situations because of their facial difference and some of the features associated with it, such as speech. Mothers also recognized this tendency in their daughters. However, as many of the dyads describe, this isolation and insecurity arose as their daughter aged, and was particularly accentuated in their transition into adolescence and high school.

Nevertheless, throughout the interview process, both mothers and daughters cited very similar positive contributions of facial difference to their individual lives, specifically a pronounced sense of personal strength, and a greater awareness or respect of other people. For the dyad however, there were a number of ways that both parties felt that facial difference had enriched their relationships, which all together culminated into one overarching theme termed "exquisite attunement" discussed below.

**"I've had to be tough, right?": Developing personal strength.** Many of the mothers discussed that their life experiences, shaped by raising a child with a facial difference, has made

them a stronger, more resilient person. The majority of the individuals recognized that they have personally experienced many difficult events, and transitioned through challenging periods that people not touched by facial difference could not or would not understand. Some mothers used these trying experiences as their rationale that they can not only continue to face adversities as they arise, but overcome them. Moreover, a number of mothers discussed that their experiences, particularly within the medical system, at school and in other social situations, have pushed them to be more assertive in general, or question things whenever possible.

For example, Lee stated: “It’s definitely made me a stronger person. It’s definitely taught me to question stuff.” Ellen suggested: “It has made me a stronger person because I had to be the advocate. I had to speak up more, I had to keep my eyes and ears open more.” Robin and Margaret concurred in their responses saying, “I think it’s made me a little more assertive than I would have been otherwise because I had to be her advocate when she was smaller,” and “I think because I felt like I had to advocate for her and speak up and express my opinion more, I think it’s made me a stronger person.” In speaking of her personal strength, Alison reflected on the fear associated with having a baby with a facial difference: “I’ve had to be tough, right? It isn’t easy to have a baby born where they’re telling you that she’s going to have multiple surgeries for the rest of her life.”

What is interesting to note, is that while mothers were readily able to identify this personal strength in themselves, daughters seemed less able to do so. Only one daughter pointed out that her experiences living with a facial difference made her stronger. Nessa stated: “It’s made me stronger cause I can handle a lot more than I ever could before.” Daughters also were unable to recognize this sense of strength in their mothers. However, mothers very readily discerned this quality in their daughters. Speaking of her daughter, Beth said, “She’s so brave.

Compared to other kids who have no problems...she takes everything like a trooper. Never once, ever complains.” Similarly, Lee recognized: “Sure, there were some ups and downs...there were some sad times, some frustrating times, but it all builds to, I think, her developing into a better person.” “If anything,” Saoirse said about her daughter, “the whole process from start to finish has made her stronger...it has made her understand that she can take on anything and survive it.” Alison also noted: “I think that she, in a way, will always be tougher because of what she’s been through...she’s very strong...she’s tough. She can handle a lot.” Marcia demonstrated her pleasure with the strength her daughter exemplifies, when she states: “She’s a fighter. I’m very proud to say that.” Finally, Jane reflected on her daughter’s ability to deal with “adversities”: “For all the ailments that she feels daily, she’s just not a complainer, and I think that’s a huge strength. She’s such a pillar of strength...like, a really, really strong kid.”

**“They’re going through stuff too”: Cultivating awareness and respect of others.** A

number of the dyads also alluded to the ways in which they felt facial difference made them more aware of and respectful of other people. Mothers described an increased sense of compassion and tolerance for others, regardless of differences or disabilities; many citing that something had changed within them after giving birth to a daughter with a difference, or having their daughter diagnosed. In Beth’s case, she felt that she “became a more kinder, softer person.”

She said:

Although I had it in me, I didn’t always show it. But now, I tend to show my soft side more. I’m more understanding; more accepting. I include others more. I needed it. I feel like I was given this for a reason. I needed to grow.

Ellen also articulated:

I’ve become more open that everybody has issues. Some of them are more visual. There are a lot of ailments out there, mental, physical...some are more visual than others...everyone has something to deal with... I’ve learned to treat

everyone, with or without a facial difference, or with or without a disability...to treat everyone equal, fairly; to give people a chance.

Lee made a similar conclusion, when she stated: “You learn to just deal with what’s in front of you...appreciate what you have and be easier on other people; to respect, and be fair with them cause they’re going through stuff too.”

Some of the mothers suggested that their experiences raising a child with a facial differences resulted in their wanting to be more actively involved not only within the community of individuals touched by facial difference, but in society as a whole; educating people to be more accepting and nurturing. Adina, for instance, believes she changed, and stated:

It’s so interesting how you are more open. After she was born, my eyes were more sensitive to facial differences. You kind of see things now that you might not have paid attention to before...I am more helpful. I am more understanding. I am more involved in charities...I do feel like I’d like to help more.

Mothers were equally as likely to recognize this trait in their daughters. In speaking of her daughter, Beth stated: “She’s always thinking of others before herself. She’s just so kind and gentle. Robin also commented that her daughter “specifically makes a point of making friends with other children that she sees are being isolated, or are alone.” She feels it has helped her daughter “be more compassionate than some of her peers...sort of empathize with people a bit better.” Alison’s felt her daughter did the same: “She’s just such a good soul. She gets people. She’ll sense something in someone and she’ll just make an extra point of being kinder to them.” Saoirse noted that her daughter “gets so angry if somebody picks on a difference, whether it’s a physical difference or a mental difference, even just a difference of style.” She says, “If somebody is bugging somebody because they’re different, she gets mad, and she will stand up for them. It’s not even a tolerance of differences, it’s a defense of differences.” Some of the mothers of the older girls even felt that this quality influenced their career choices, like Liz who

mentioned: “She’s a very positive person; very supportive of others and very helpful. She likes to help others and that’s probably why she’s going into the communicative disorders field.”

Unlike personal strength, daughters did note that their experiences made them more cognizant of individuals living with various differences and disabilities, and increasingly sensitive to their needs; specifically, many of the daughters discuss their efforts to treat individuals with respect and kindness, or come to their defence when necessary, because they understand how it feels to be treated in an unpleasant, marginalizing, and isolating manner. Amber explained: “I’m more accepting...you’re able to connect with more people and understand more people. Like, you’re less likely to judge, and you try to connect and understand what people are going through and not just take it for...what’s being seen.” “I’m not as judgemental I don’t think either,” Avery said, “I’m more accepting of people. Like, it doesn’t matter really...facial difference or a disability or whether it be mental illness...it doesn’t matter to me. I just see them for who they are.” Alexa mentioned: “I can see other people’s facial differences in other places, and I don’t stare at them because I feel the same way.” Nessa also believed: “I have more of an appreciation for people with facial differences and what they go through...if I see other people, now I’m very understanding...I don’t judge people at all. I do not think of anyone as ugly...”

Delilah commented:

I’d say that people can be really mean to people who look different from the normal, and that really bothers me because they don’t take the time to get to know the person; they just judge them on how they look. I’ll talk to the person...I’m not going to judge them on what I see.

Cheyenne also considered her openness, stating:

I’ve been taught to be more open and look inside a person rather than what’s on the outside, because what’s on the inside might be different than what’s on the

outside...yes, they might look weird or more different than normal on the outside, but on the inside they might be the nicest people you'll ever meet on this planet...accept other people's differences, whether it be a facial difference, a disability, sexuality, or anything like that.

Sabrina thought that her experiences living with a difference also gave her the power to advocate and educate people on acceptance:

People are afraid of stuff...they're more likely to bully someone who is different, and I just don't want other kids to go through that...I hope to...sort of like, educate people about that and advocate for people who either have like disabilities or facial differences at school, and...be a resource for them to talk, and help them cope with feeling different or alone.

However, despite being able to recognize this quality in themselves, many of the girls made no reference to this trait in their mothers.

**“We fight, together”: Exquisite attunement in the mother-daughter relationship.**

Within the relationship, the contributions of facial difference were vast. Many dyads discussed a variety of ways in which they felt exceptionally in-sync with their mother or daughter, and referenced how their relationship was made stronger as a result of the facial difference. This unique sense of intimacy was multi-faceted, as described below, but was considered under one original umbrella label, titled “exquisite attunement”. While a number of dyads referenced challenges in the relationship given adolescent transitions and differences in opinion (i.e. disagreements around the daughter's curfew, relationships, dress, and friendships), the majority still referred to a sense of extreme closeness between mother and daughter stemming from the experiences related to living with and raising a child with a difference; some, like Alison, went so far as to suggest: “as a mother-daughter relationship, we're probably more like best friends because we've been through so much together.” Avery echoed this sentiment, stating: “My mom is one of my best friends.”

For the majority of the pairs, this closeness came as a result of the large amount of time spent together. Alison for instance, continued to say, “It’s made us tighter cause we have to go through...everything, just the two of us. We fight together each time.” For others, it revolved around the intimacy with which conversations were had given the sense of openness and honesty they felt characterized their bonds. Delilah claimed, “We’re close I guess because we’re pretty open with each other.” “Our relationship is such a good relationship...I feel like I can tell her anything,” Cheyanne claimed. Lee described:

I really love the fact that we can really talk about things. I think that’s a real highlight because I know other women that their daughters are like, ‘Go away, I don’t want to talk to you,’ slamming the door in their face. We don’t have that type of relationship at all. We spend a lot of time together...from the very beginning we’ve always been kind of together and experienced a lot of things together.

Saoirse also explained:

She and I have a really close relationship...it’s kinda interesting because she sees me as a friend and a parent...she has no fear of asking me any question, and I have no fear in answering any of the questions she asks me. There’s a lot of openness there.

Jane similarly asserted:

She is very open with me. She comes to be about a lot of things that I’ve heard from my other friends, that they don’t get the same kind of communication...one of the things I love is that she is willing to come to me and talk to me about anything, and you know, listen.

Although there existed this sense of intimacy, many of the mothers and daughters were readily able to identify the ways in which the other member of the dyad was an independent or unique individual, with their own, sometimes different, thoughts, opinions and beliefs and interests. However, many expressed a desire to learn from and emulate the other person. For example, Beth stated:

She's like a mini-me, only better. I wish I had her wisdom...I learn from her every day. She has so much more than I ever had, and more than most people will ever have as far as gentleness, and kindness, and thoughtfulness. She's got what we all strive for.

Similarly, Ellen mentioned how her daughter is "becoming a better person" than she is, and Alison credits her daughter with teaching her "more than I've taught her, really". Adina recounted a specific lesson that her daughter imparted on her in their daily interactions:

It happened last year, she finished grade eight and they were preparing for...final pictures. And in the morning before she left for school, I said to her, 'Don't you want to put make up on your face to make you look pretty in the pictures?' And she said, 'No. This is how my friends know me; this is how they like me. I don't want to look different in the pictures.' From a fourteen year old, it was a life lesson for me. I try to help her, but sometimes, she helps me as well. Sometimes she teaches me lessons, and that was a good one to learn.

Sabrina commented: "My mom's always been very focused on giving and on helping others and stuff, and that's something that I value as well. Like, I'm going into teaching. She's a nurse, and obviously that's a helping profession too." Jordan also looked to model her mother's personality: "My mom's just a positive person. When you talk to her, she's friendly. So I always thought that was really important...And I think that's something that I've learned. I like to be friendly when I'm talking to someone." Nessa also admired her mother's forgiveness: "I keep a lot of grudges, which is not by best quality. I really wish I could be more like my mom because she's so good at forgiving and understanding people...from that aspect, I wish I was more like my mom."

Moreover, the dyads appeared to be very in-tune with each other. Mothers were extremely aware of and sensitive to their daughters' emotions and experiences around the medical system, families, school and the social world; often discerning and respecting how their daughters felt about these events and encounters without an explicit discussion. "I get kind of anxious in social settings," Avery admitted, "So, she kind of picks up on that. She's really good with that." Alison noted: "if she's upset or worried, I can sense it in her actions and everything."

Margaret admitted: “We both know exactly what can push the other one over the edge, and exactly what the other person needs sometimes.” Interestingly however, many of the daughters, regardless of age, demonstrated this same sensitivity to their mothers’ emotions and experiences, with many having made reference to the difficulties associated with raising a child with a difference. Lee, for example, remembered when her daughter was preparing for surgery:

One of the questions she had was... ‘Well, what would you do about work?’ And I said, ‘I’ll be there. That’s for me to worry about. You don’t need to worry about mom’s schedule’...That kind of threw me for a bit...not only is she worried about herself, she’s worried about me.

Ellen also recalled an instance before her daughter when into surgery:

She got very panicky...just very weepy before going on. She kept apologizing to me for being the way she was. She kept saying, ‘I’m sorry you didn’t have the perfect baby. I’m sorry I’m putting you through this.’ She kept saying, ‘I wish things were different...I’m really sorry that you didn’t have the daughter you deserve. You deserve better than me.’

Amber stated:

I think it’s the same thing...it [talking about surgery] upsets them [mothers] too. Like my mom gets worried and stuff for me...it’s kind of upsetting or stressful...I care about her too...like, I want to be supportive...cause she’s that way for me.

Ruth described that she understood how her mother coped with stress: “My mom...the way she deals with stuff is my talking about it. So, she’s dealing with it too, cause obviously your parents are nervous, also.” Delilah recognized that she “was not the easiest child to deal with”, and Jordan “felt bad” that she “took up so much of her [mother’s] time.” Avery, too, explained: “Since she’s so supportive and loving, I find that I’m that way towards here. Like, I try to be as supportive as I can towards her...when she wants to talk, I’m like, right there.” She went on to describe a certain instance where she felt she was particularly sensitive to her mother:

I was at the doctor’s office and there were these two women who brought their babies. And they were just going on about the baby life and stuff like that. And my mom was kind of watching them...and I’m like, ‘I’m really sorry cause...you

didn't have that...your kid was at the hospital...I'm sorry because you don't even know what they're talking about.

### **Mothering Differently**

One of the aims of the study was to understand the ways in which a woman may mother differently when she, too, is living with a facial difference. Three of the twelve mothers who participated in the project were living with the same difference as their daughters. While no explicit questions were asked of these mothers concerning this research question, the transcripts of interviews from these three women were compared to the responses given by the remaining nine mothers to highlight potential parallels or disparities.

**Roles and remorse.** Overall, there were a number of similarities between the reflections of women with and without facial differences. Mothers and daughters' responses to the first set questions were particularly consistent; the majority reflected on being their daughters' advocate, co-ordinator, gatekeeper, liaison, educator, and support system. These analogies suggest that mothers occupy the same roles in their daughters' lives, regardless of their personally living with a difference or not. There was no discussion of additional roles for mothers who were also living with a difference from either member of the dyad. Furthermore, mothers played a similar part in helping their daughters transition through adolescence, making use of both personal stories and explicit and implicit messages of validation, encouragement and empowerment. Mothers with and without differences were also equally as likely to address issues of gender, body image, relationships, sexuality and identity with their girls.

What is perhaps more interesting, however, is the common experience of guilt in the reflections and responses of the mothers. The large majority of mothers, with or without facial differences, discussed how they felt guilty for their daughters being born with a facial difference,

and many blamed themselves when searching for answers as to why. Some like Lee, cited genetic origins that had possibly been transferred through their bloodline:

The geneticist...came in, took one look at her and said, 'Oh yeah, she has Treacher Collins.' And I was like, 'Oh, well, what is that?' And he looked at me and said, 'Well, you should know, you have it too.'...I kind of pondered...once in a while, that she got TC from me.

Liz similarly felt a lot of guilt: "...because I had a cleft...there's always that, 'It's because of me, it's my fault.' It was always like, 'Did I do something during pregnancy?'" Marcia also questioned: "'Why did it happen to me? Where did it come from?' There is no one in the family with Cruzon's, so sometimes, I question myself."

Others like Ellen, explained their daughter's difference around events that had taken place during pregnancy:

I think a lot of the time, I feel guilty...it's stuff in my environment at the time. When I was pregnant, I had a bad virus at the beginning of the pregnancy, so I was quite sick. I was a nurse and working with some chemo patients, and probably working with some things back then that they were not as aware of. I feel like my environment caused her to have a birth defect.

Adina also felt guilty, saying:

At the beginning...you think it's the end of the world. You ask, 'Why? Why did this happen to me? What did I do wrong?' And then you blame yourself, of course, like, 'It's my fault.' Not in the way that you did something physically, but you think spiritually like, 'Who knows what I did to God in this world that He punished me in this way?'

Moving beyond birth and infancy, many mothers also felt guilty around some of the decisions that they had made regarding their daughters' care, or the consequences that had stemmed from some of the roles they assumed in their daughters' lives. Beth, for instance, recounted: "Maybe I jumped too fast at doing surgeries that maybe weren't the best...because I thought that it would be good initially, but in hindsight, it wasn't." Ellen also experienced guilt around surgeries, explaining: "After this jaw surgery, she feels it's made some outward

appearance changes to her nose...now, I feel really guilty about it.” Lee also remembered hesitating at times because, “I was kind of accused of being a helicopter mom...always hovering. I didn’t know how else to be.” Jane reflected on her role coordinating her daughter’s social circle and states: “I really feel that it’s done more damage than good for her...And I blame myself a lot for that because I didn’t have the opportunity to really...I guess, be brave enough to...just break away a bit [from their group of friends].”

**Similarities versus singularities.** One imperative difference that was found in the narratives of mothers with facial differences was the ability to both identify with their daughter, but at the same time, recognizing their individuality and unique experiences. Given that the mothers shared in their daughters’ difference, the members of the three dyads recognized that they did share in one aspect of their identity. However, mothers were often quick to note that there were significant differences in their journey and their daughters; namely, all of the mothers acknowledged that their differences were by no means as pronounced as their daughters, and that facial difference did not play an extremely influential role in their development. For Liz and Adina, their differences were small and could be concealed. Adina mentioned: “I do have a little bit of a port wine stain as well, but mine is very, very minor...it’s not directly on my face. It’s a little bit on my chin and on my neck.” Liz also differentiated the two differences: “Mine was an incomplete unilateral [cleft-palate], and obviously hers was a complete bilateral cleft-lip and palate. Mine was just the lip.” For Lee, her Treacher Collins was so mild that she was completely unaware she had it until her daughter was born, as demonstrated in her quote above. As such, these mothers felt and acknowledged that the influence of facial difference on their lives was not monumental, and that they were not subjected to the same challenges and obstacles that their daughters were, thus, they each felt they could not draw parallels between their own lives and their daughters’. For example, Adina explicitly stated: “I got teased sometimes in

school. Of course, it's not in the same way. It's not comparable." Liz also ascertained: "Mine wasn't as severe...I definitely think that it's something we've shared and we can relate to each other, but...a very different road. I mean, I think I had two surgeries, whereas she is on number eighteen now." Lee clarified that she "shares some things, but not everything." While she doesn't "want to pretend" that she doesn't have it, she states that she "simply didn't to some extent, like [her daughter]...I would never pretend to know what she's going through...I don't walk in her shoes. I don't know."

The other nine mothers who did not have a facial difference were also cognizant of the fact that their daughters had endured pressures and stigmatization that they were personally unfamiliar with in their own upbringing. However, in an effort to be supportive and nurturing, these mothers attempted to make comparisons between their daughters' experiences and the experiences of wider society; specifically, many sought to comfort their daughters by reminding them that every person had something they disliked about themselves, or something they were uncomfortable with. "I think I've tried to show her...everybody's different; everybody has some different that they're not proud of, that they're not confident with...whatever," Maureen said. Similarly, Margaret mentioned: "I think a lot of the middle school years are not easy for adolescent girls...just sort of the pressures. I think there's a lot more worry about how they look, what they're wearing, that whole piece for everyone."

Although many daughters understood that their mothers were trying to be helpful, these messages were often not appreciated or well-received. Some daughters, like Sabrina and Nessa, felt that they emphasized their mothers' naivety around the realities of living with a facial difference, making it hard to relate to them in these instances. "I get upset because I feel like she doesn't really understand," Sabrina said. "She'll make parallels between like, 'Oh yeah, I hate

my hair.’ And it’s like, ‘No. It’s not the same thing.’ It’s like, ‘Oh, everybody has something they don’t like about themselves.’ It just sort of minimizes it.” Nessa also articulated:

Unless you have a facial difference, you really don’t understand how self-conscious you are. I think sometimes my mom, like, she tries to understand, but she’s really pretty and she’s kind of been really pretty her whole life...she never really understands why I feel so nervous or get all freaked out if someone is staring at me. In that part, she can’t really help me, and it makes it worse because she’s like, ‘I don’t understand why you’re being so difficult.’

### **Discussion**

While presented as distinct themes in the above results section, there are a number of ways in which the data from each research question are interconnected. The roles mothers play in their daughters’ lives are undoubtedly intertwined with their roles in their daughters’ adolescence. Furthermore, these roles assumed by mothers, with or without facial differences, influence the way they relate to their daughters overall. There also exist a number of parallels between the data summarized and existing literature from within disability and critical race studies. The analysis of these themes goes beyond simply understanding the implication of the findings for the mother-daughter relationship, however. Instead, critical analysis of these themes reveals a number of issues inherent within the social environment and culture in which individuals and families living with physical differences and disabilities exist. The associations between the research questions and an examination of the social context will be highlighted in the discussion below.

## **The Normal/Abnormal Dichotomy**

As demonstrated in the previous section, mothers are extremely active in their daughters' lives, particularly in the realm of social interactions, the medical system, family relationships and the media. In many ways, these roles can be interpreted as parallel to the gendered ideology of care and proactivity that Traustadottir (1991), Klein et al. (2006) and Rice (2014) discuss in their work: similar to the mothers that these researchers investigated, the mothers interviewed within this study, with or without facial differences, are all heavily involved in providing support in the medical and education systems, seeking out new and diverse information and services, and interacting with the various professionals who comes into contact with their daughters. Perhaps most importantly however, many of the roles and responsibilities that mothers assumed helped facilitate the creation of a space in which their children felt protected and accepted; by way of their involvement in doctor's appointments and surgeries, schools and classrooms, family and the media, mothers did their best to ensure that their daughters were not the subject of stereotyping, stigmatization, or unfair treatment. Similarly, mothers' role in their daughters' adolescence and process of becoming women mirrors the same provision of safety and approval. In openly communicating with their daughters about a variety of critical issues in the lives of their adolescent girls, and focusing on validating, empowering and encouraging their daughters, mothers are fostering a relationship characterized by acceptance and nurturance.

Moreover, within the various roles summarized, there is evidence that the mothers included in the study exemplify Traustadottir's (1991) different meanings of caring: mothers are both "caring for" their daughters by taking on some of the challenging tasks such as a medical advocate, social defender and educator, as well as the family liaison, and simultaneously "caring about" the child by being sensitive to their daughters' needs and experiences, and providing

them with both emotional and physical support when necessary. Mothers may also have adopted the “extended caring role” in raising a daughter with a physical difference; given the greater awareness and respect of others they feel facial difference has afforded them, mothers often extend their care beyond their daughters and into the broader community of individuals and families touched by facial difference, and society as a whole. Consequently, as demonstrated by the exquisite attunement described between the mothers and daughters, the high degree of involvement in their care and experiences enables the mothers to understand their daughters’ needs and journey unlike many others, and forge a strong bond with them, as McKeever and Miller (2004) suggest.

Of course, a number of these roles stem from the unique experiences of raising a child with a physical difference, disability or chronic illness. For families who are not touched by these experiences, there is rarely a need to act as a child’s medical advocate given many children do not interact as regularly with the medical system and doctors as those with facial differences, nor do they undergo such extensive treatments and surgeries. There is also seldom any social education to be done to prepare individuals for meeting and interacting with their child, and there is less of a need to help extended family members adjust to their child, or convey information to them around the child’s physical health, surgical procedures and recovery. Naturally, the interaction with the various systems and the necessities inherent within each role differ based on the type of facial difference, but simply put, the unique events and encounters involved in raising a child with a physical difference thrust mothers into roles that unaffected families are unlikely to encounter. Some of the experiences and responsibilities inherent within raising a child with a difference are fundamentally unlike those involved in raising a child without one.

However, this is not to say that mothers' experiences raising a child with a physical difference are entirely distinct or unfamiliar. Instead, a number of their roles are extremely similar to the duties and responsibilities assumed by parents raising children without facial differences. For instance, some developmental literature has described the ways in which mothers foster their children's social skills by presiding over the organization of their social lives, particularly early on (Lareau, 2000; Updegraff, McHale, Crouter, & Kupanoff, 2004). Additionally, there has been a wealth of literature on the roles mothers play in defending their children socially, mainly in instances of bullying (Georgiou, 2008). There is also a large amount of research done on the ways in which mothers act as gatekeepers for their children, actively regulating what types of media their children engage in (Pasquier, 2001). Similarly, mothers raising daughters without physical differences and disabilities describe adolescence as a particularly challenging and confusing time, with the issues of relationships, gender, identity, body and sexuality surfacing repeatedly in conversations and interactions with their girls (Diiorio, Kelley, Hockenberry-Eaton, 1999).

Altogether, these parallels signify that families touched by facial differences are by no means abnormal; that the job of a mother raising a child with a difference is not entirely dissimilar from one raising a child without one. In fact, many of the mothers interviewed within this study made reference to a number of their roles being assumed in their dealings with their other children who did not have a facial difference. Naturally, given their child's increased potential for marginalization and stigmatization, there may exist a heightened need for parents of children with differences to assume these familiar roles more frequently, or earlier in development. Overall however, the recognition of the underlying similarities is missing in the current conceptualizations of families touched not only by facial differences, but physical differences and disabilities as a whole.

## **The Origins of Role Strain**

While many of the roles mothers take serve as positive forces in the lives of their daughters, providing a safe and accepting space as outlined above, the challenges built into raising a child with a difference are often the focus of much of the existing literature on facial difference. For example, caring for an affected child has been found to negatively impact parents; 12% of those with affected children are separated or divorced, while 6% suffer from mental health issues such as anxiety and depression (Broder & Strauss, 1991; Lefebvre & Munro, 1978). Mothers are particularly vulnerable to increased personal stress, often feeling less competent in their ability to parent, and reporting more marital discord and family conflict (Speltz et al., 1990). It has also been reported that a substantial portion of behavioural changes in families with affected children, such as physical exhaustion, lack of sleep, decisions not to have more children, and leaving employment to remain home, are reported to come as a result of stress (Versluys, 1984). Some of these obstacles parallel the tensions and stressors that mothers cited in this study. Others, such as mothers balancing medical decisions with acknowledging their daughters' opinions, or navigating their gatekeeping role in a way that respects their daughters' autonomy, are not widely noted in research on facial difference.

This discussion of challenges or obstacles, similar to much of the existing literature, is informed by the deficit model of disability, and posits that raising a child with a difference ultimately destabilizes or takes away from the life of a parent (Austin, 2009; Rice, 2014). However, as mentioned in the literature review above, these assessments do little to critically address where these tensions and stresses stem from or why they arise; the existing literature ignores the significant and overwhelming pressure that society places on mothers raising children with physical differences and disabilities (McLaughlin et al., 2008). As previously

cited, the literature is therefore in need of a shift away from promulgating raising a child with a disability as taxing, and a push towards identifying and eliminating the social barriers that parents face in their interactions with various systems that complicate their journey (Cole, 2004).

In the case of the twelve mothers interviewed for the present study, the burden of keeping their daughters well-connected and remaining constantly aware of their relationships was exhausting, given their recognition of the potential social difficulties their daughters could encounter because of their facial differences. The same is true within the family: mothers were aware of other members' discomfort and uncertainty, and consequently did whatever they could to make their daughters' facial differences seem less intimidating or overwhelming. In this regard, mothers are consistently trying to compensate for society's rejection and ignorance, and act as the buffer between their daughter and the damaging attitudes of the wider culture. If the views on disability and difference were less adverse, perhaps mothers would feel less of an obligation to uphold their role as co-ordinator, defender, educator and liaison, therein allowing them to feel less stressed and conflicted.

The same is true for the tensions around the medical system and media. Mothers are trying to strike the correct balance between making difficult decisions and caring for their daughters, and this challenge is further complicated by external messages from these systems regarding what is "acceptable", "normal", or "best" for their children. Moreover, these systems are replete with messages around what constitutes a "good" or "responsible" parent. Subsequently, mothers are frequently left questioning themselves and the job that they do, undoubtedly adding to their overall stress.

## **The Prevalence of Mother-Blame**

The origin of the role strain and maternal pressures discussed above may be tied to the discourse of mother-blame. The cultural ideals of what mothers “should be” and “should do” are powerful socializing forces that begin for girls in childhood, and continue into adulthood, becoming engrained in a woman’s subconscious, so that the unattainable expectations become part of her common-sense knowledge (Singh, 2004). Mothers today frequently compete with the idealized portrait of the “good mother”, characterized by qualities such as understanding, security, intimacy, wisdom, selflessness and harmony; while vehemently trying to avoid the label of “inadequate mother”, plagued by neglect, negativity, ignorance and passivity (Singh, 2004). However, these judgements are particularly harsh and pervasive when the child is living with a difference or disability; beginning extremely early on and filtering into many realms of daily life.

Though not a new phenomenon, maternal behaviours before and during pregnancy are believed to be the cause of a child’s physical and cognitive condition (Landsman, 2009). When examining the historical origins of facial differences alone, the mother is implicated numerous times across various cultures: in European folklore, mothers gave birth to a child with a facial difference as a punishment or revenge for committing sins, while in Roman, Indian, Chinese, African and Native cultures, a child was born with a facial difference if the mother was frightened or experienced a traumatic event during pregnancy (Charkins, 1996). In our modern, highly technological and medically advanced society, birth and reproduction are considered individualized domains, where women are held responsible for their child’s health at birth. Presently, women are obligated to undergo prenatal screenings and regulate their uterine environment for the benefit of their baby.

While it may be true that what mothers do to their bodies can impact a developing fetus, our cultural ideals exaggerates this responsibility and problematically places blame solely on the individual woman. Thus, many women, including those in the present study, feel a profound sense of personal responsibility when their baby is born with a difference or disability, even when there exists no genetic or environmental cause. Both the guilt around “causing” their daughter’s difference, and the search for answers as to what happened, was especially predominant in the narratives of all mothers interviewed in the study, as previously demonstrated. This maternal guilt is said to be found across all types of disabilities, social classes and educational levels, which speaks to its ubiquitous nature (Landsman, 2009).

In recent years, the narrative of maternal responsibility is said to have expanded to include not only the gestational period, but the child-rearing periods as well (Landsman, 2009). Given their role in caring for and about their children (Traustadottir, 1991), mothers mediate and manage their children’s exposure to social, medical and educational spheres, and therefore lie at the crux of many intersecting blames. Overall, a child’s success is considered a reflection of the woman as a mother (Caplan, 2000), and while the mothering role is considered both “satisfying and sustaining” for many, mothers can feel “disproportionately burdened” as they compete all of these external pressures (Singh, 2004).

As Ryan and Runswick-Cole (2008) state, mothers are the parent who falls under the closest surveillance and scrutiny in society. Mothers are often held more accountable by medical professionals than are fathers (Jackson & Mannix, 2004; Ryan & Runswick-Cole, 2008; Singh, 2004), and this is particularly damaging given that our culture considers medical and mental health practitioners to be “experts” on human behaviour and development (Caplan, 2000). A number of mothers in the present study, like Jane, Lee, Ellen, and Adina discussed feeling

pressured by doctors to make their daughters continue with medical treatments and surgeries, thus resulting in a sense of conflict between respecting their daughters' wishes and adhering to medical advice. Mothers are also more readily criticized with regard to their parenting skills and abilities. Specifically, mothers feel a strong reinforcement of their personal feelings of inadequacy and responsibility in their everyday encounters with other parents, particularly mothers (Singh, 2004). This was true in the case of many mothers who reflected on feeling judged by other parents in day to day life, but particularly in the narratives of Lee and Alison, who recalled very specific, negative and invasive interactions with fellow mothers. This notion exemplifies Foucault's (1975) theory of community surveillance. As Singh (2004) summarizes:

...Every individual is both a subject exercising the disciplinary gaze, and an object of the gaze. Uncertainty as to whether one is subject or object leads the subject to internalize the disciplinary gaze and to continually reproduce a disciplinary power that has no external material center. To this extent it does not matter whether mothers are actually experiencing this judgement or "imagining" it. The point is that even their imagination reflects the internalization of this disciplinary power. (p. 1201)

Thus, the culture of mother-blame is readily reproduced by women, for women, and with each passing judgement, women embed themselves further in a culture by which they are also judged.

Thus, through deconstructing the pervasive discourse of mother-blame, it becomes clear how these messages may contribute to the stresses and pressures described by mothers within this study, regardless of whether they, too, are living with a facial difference or not. Furthermore, it may begin to explain the need for mothers to "armour" and validate themselves as good mothers by way of their resistance and reframing with their daughters. Mother-blame may also be a factor in the mothers' discussion of the contributions they feel facial differences has made

in their personal lives. The increased sense of personal strength may in fact stem from the constant confrontation of criticism imparted by others in social or medical interactions. Similarly, their sense of increased awareness and respect for others may derive from their unwillingness to participate in the maintenance of our hypercritical culture; in particular, the perpetuation of the blaming and shaming that has plagued their personal experiences as women and mothers.

Still, while there is a wealth of other factors involved in raising a “healthy” child, primary caregivers do have an important role in shaping kids’ development. Given that moms still tend to assume the role of primary caregiver however, they remain disproportionately blamed. In continuing research on motherhood, especially in the realm of physical difference and disability, it is important to be realistic about the responsibility that mothers have without blaming and shaming; acknowledging real responsibility for others and rising to this while at the same time trying to be aware of and struggle against social pressures, and the inner and outer voices that contribute to unrealistic expectations.

### **Resilience in Relationship**

The discussion around daughters’ adolescence is of particular importance to the study. As previously stated, much of the current literature on female adolescence focuses on the struggles or challenges that young women face throughout these formative years, but does little to discuss the ways they demonstrate resiliency and strength (American Psychological Association, 2014). According to the American Psychological Association (APA) (2014), there exist vital sources of “resistance to and liberation from” the wealth of negative societal messages that young girls face in adolescence with respect to their bodies, gender, sexuality, and relationships. These resources include: the ability to hear positive messages about oneself,

learning to trust oneself as knowledgeable, participation in extra-curricular activities such as athletics, non-traditional sex-typing, the availability of strong female role models, and the formation and maintenance of close family relationships.

More specifically, the APA (2014) suggests that adults in the girls' environments, particularly mothers and "other mothers" should provide girls with the experiences and opportunities to "understand, engage with, and transform" the cultural forces and messages that they feel limit them and causes them harm. These relationships, termed "hardiness zones", create engaging spaces for girls that allow them to "access skills, relationships, and possibilities that enable them to experience power and meaning" (p. 5). In many ways, these guidelines mirror the Jungian and feminist opinion of development summarized earlier, which highlights the importance of a close and enduring mother-daughter relationship in empowering adolescent girls (Debold et al., 1994; Lowinsky, 1992; O'Reilly, 1998; Pipher, 1994; Rutter, 1996).

The idea of the exquisite attunement that exists between mothers and daughter signifies the importance of the relationship to both parties, but moreover, the themes that arose within the interviews with both mothers and daughters parallel those the APA deem essential and protective. Through their open communication with daughters regarding adolescent issues such as body, gender, and sexuality, mothers help to promote their daughters' acceptance of a range of appearances, bolster their daughters' sense of individuality, and encourage their daughters to explore their relationships. Mothers also foster meaningful participation in school and community organizations by supporting their daughters in whatever activities they desired to pursue. Each of these is critical to strengthening young girls in the face of some difficult adolescent transitions (APA, 2014). Thus, it can be said that the mothers in this study act as "hardiness zones" for their daughters.

The themes found also reflect those that Bell and Nkomo (1998) put forth in their work on armouring. In their study on racial oppression, Bell and Nkomo (1998) emphasized the role of Black mothers in socializing their daughters to “function cognitively and emotionally” in the face of racism and sexism; two intersecting identities which can serve to erode a young girl’s sense of “self-worth, dignity, and beauty” (p. 286). The messages integrated into the girls’ sense of armour included: being respectable and carrying themselves in a dignified manner; developing courage and a sense of individual beauty, grace, style and intellect; selective exposure to communities and activities that reinforce their self-image, increase their confidence, and enhance social skills; becoming self-reliant and taking care of themselves; and being strong.

The messages communicated by mothers in the present study are quite similar to those conveyed by mothers in Bell and Nkomo’s original study (1998), and served to likewise defend against the intersecting forces of sexism and ableism that daughters with facial differences confront. Through their discussions and stories, mothers communicated to their daughters the importance of neither feeling ashamed of nor exploiting their bodies, and supported their daughters’ sense of style in dress and make-up. Similarly, many were extremely proud of their daughters’ academic successes. In using messages that centered on validation and empowerment, mothers also readily taught their daughters that they were strong and self-reliant. Finally, mothers encouraged and espoused their daughters’ involvement in various activities and communities, recognizing the ways that it aided in developing and maintaining their daughters’ sense of self. As demonstrated in the narratives of the daughters, many of their mothers’ messages and lessons were taken in and used as protection in the face of the stigma and marginalization they encountered on a regular basis because of their physical appearance, but also as they transitioned through the sometimes difficult adolescent terrain. Thus, the mother-daughter relationships described in the present study served as a positive force and secure base

as daughters began to explore their own identities and the possibilities that opened up to them in early adulthood.

There are two important notes to be made here, however. The first is in the distinction that Bell and Nkomo (1998) make between two categories of families studied, and the differences in the types of armour that stem from their unique experiences. The first type of family studied was labelled “families of nurturance and support”, wherein daughters reported that their parents, particularly mothers, provided unconditional support and love, while maintaining a sense of authority and discipline. These nurturing and supportive families more readily communicated the messages of being respectable and courageous. Alternatively, “families of struggle and survival” experienced “some kind of periodic trauma that temporarily unstabilized” the family dynamic and daughters’ life (p. 290). Consequently, mothers from families that experienced this instability and struggle were more adept at communicating messages of strength and self-reliance. It is clear that in the present study, mothers help navigate their daughters through adolescence with the use of messages representative of both categories of families, suggesting in a sense that the families of the women interviewed could be characterized as nurturing, loving, and disciplined, but that they also moved through periods of particular challenge. This supposition is consistent with the overall tone of the interviews with the mothers and daughters; both members of the dyad make reference to ways in which they have been faced with numerous obstacles, but always revert back to the way in which their relationship was especially close and secure. Again, an important distinction must be made: by no means does this connection suggest that *having* a facial difference or *raising* a child with a facial difference is “unstabilizing”. Instead, the social, medical, and sometimes economic burdens imposed on families touched by facial difference summarized above serve as significant

obstacles for both mothers and daughters, but by no means impede or undermine the environment of unconditional love and nurturance mothers aim to provide.

**Intersection and passing as protection.** Second, and vital to the overall discussion around mothers' role in adolescence, is the lack of significant differences between the narratives of mothers with and without facial difference. Bell and Nkomo's study (1998) was selected as a parallel theory to this investigation because it highlighted important intersecting identities in the lives of the women interviewees. Originally, it was purposed that women with facial differences could mother differently, given that they shared in the intersecting identities that their daughters embodied: both "woman" and "facially different". While clearly different from the intersection of gender and race, it was assumed that having experienced life, in particular adolescence, as a girl living with a facial difference, mothers would be markedly in tune with what their daughters experienced, and thus, able to impart some "expert" advice. This was not the case, as demonstrated in the results. This sharing of intersecting identities did little to alter the dynamic between mothers and daughters: mothers without a facial difference were equally as likely to communicate the same messages of validation, encouragement and empowerment with their daughters, and daughters were just as likely to internalize these messages as a means of self-preservation and self-protection. However, this remains an area for future investigation, given the small sample of mothers interviewed who were also living with a facial difference.

Alternatively, the theme of disentanglement found within mothers' discussion of their daughters' adolescence traversed those with and without facial differences. In attempting to separate the challenges pertaining to adolescence/becoming a woman from those stemming from facial difference, many of the mothers essentially attempted to tease apart their daughters' two intersecting identities. For the daughters however, this separation was impossible to make, which

speaks to the necessity understanding social identities as intersecting rather than additive. This may also have impacted the daughter's inability to consider the ways in facial difference had made them stronger personally. Although mothers were able to recognize this trait in their girls, daughters may find it more difficult to consider themselves as becoming someone or something new through living with a facial difference; instead, they may simply understand this trait as part of their embodied being. Much like the intersection of adolescence facial and sexual difference, daughters cannot tease apart who they are from who they could be or what they are going through. For many, the challenges and "adversities" that come with being female and a having facial difference are so intimately integrated into their sense of self that they do not recognize their own strengths or challenges, but instead, regard these as "just being me".

While mothers without facial differences may not be as intimately familiar with their daughters' intersecting identities and undertake the separation of the self from facial difference with the best of intentions, the same theme of singularities versus similarities certainly points to the ways in which the mothers with facial differences comprehend and acknowledge their own differences. This directly relates to the notion of "passing", whereby people on the outer edges of a marginalized identity, be it sexuality, gender, race or disability, can move through the world as "normal"; fitting within the confines of the preferred, mainstream identity (Titchkosky, 2003). Within the realm of disabilities, the ability to pass is sometimes done voluntarily, but can also be done involuntarily, whereby individuals are not perceived as different or disabled until attention is drawn to it (Wendell, 2001). Regardless of how it is done, passing is associated with a number of advantages, including avoiding daily acts of prejudice and discrimination that people with very obvious disabilities encounter on a regular basis (Wendell, 2001).

The intersection of “female” and “facially different” identities may not be as prominent in the lives of the mothers interviewed, given their views on their differences. As summarized previously, each of the three women made reference to the ways in which their differences were milder than their daughters’, and therefore, less noticeable. Consequently, the mothers interviewed passed involuntarily, and their facial difference was not as readily integrated into their overall understanding and perception of themselves. However, this refutation of their own intersecting identities does not take away from the fact that they do acknowledge it in their daughters, and that they recognize their daughters’ lived experiences as unique to their own.

### **Improvisational Parenting**

All in all, there exists a large, overarching connection between each of the research questions and results that has important implications for the mother-daughter relationship and families touched by physical differences and disabilities as a whole. As demonstrated in the literature review and in some of the previous discussion, there exists a wealth of literature that both pathologizes and seeks to inculcate families touched by difference and disabilities, especially mothers. However, it remains important to remember that many mothers have little to no experience with disability before the birth or diagnosis of a child with impairments (Greenspan, 1998), and there exists no guide to appropriate parenting of children with disabilities (Middleton, 1999). There is undoubtedly a learning curve for women who have previously given birth to children without health concerns, and an even steeper one for women who became first-time mothers to children with a physical difference or disability.

Moreover, while the family unit is the critical site for supporting and nurturing children with physical differences and disabilities as previous research suggests, the harms and hurts visited on the individuals living with the differences can be particularly damaging, and felt by

other members as well. Families touched by facial difference, or any physical difference, are equally subject to extremely salient stigmas and pressures from the systems that surround them, including the media, the educational system, the medical system, the family system, and the general public, as demonstrated in the narratives of many of the dyads interviewed in the study. Many daughters, like Nessa, Avery, Amber, and Sabrina made reference to the importance of “looking beautiful” and competing with images of perfect models and Hollywood stars, the challenges around consenting to and undergoing medical treatment, the difficulties inherent with social interactions. Mothers like Lee, Ellen, Jane, and Robin were very much aware of the challenges their daughters faced within these systems, and made reference to the pressures and uncertainty they felt to help their daughters navigate these experiences and associated emotions. As such, individuals and their families exist within a social milieu that is unlike the one that individuals and families without differences are exposed to, and therefore, they cannot be held to the same standard of what constitutes “good parenting” or “normal” parent-child bonds. Thus, it is inappropriate to deem the actions of some mothers as constraining, oppressive or normalizing for their children, as some of the research does (Ryan & Runswick-Cole, 2008; Veck, 2000). Parents, like the mothers in this study, make their way through the numerous issues that arise as best they can, and play the roles daughters want them to play, as well as those they comprehend as necessary and vital to their daughters’ health and success.

Of course, these transitions are not met without their own challenges, as previously discussed. Each of the mothers discussed treading the line between being protective and allowing their daughters to “fend for themselves”; and daughters likewise recognized the ways they need their mothers but desire more independence on occasion. In this sense, many of the mothers interviewed acknowledged the important, yet difficult training component involved in their role. Each felt the need to navigate their daughters through adolescence and various

systems to ensure their physical and emotional health, but also a sense of responsibility to “train” their daughters to care for and believe in themselves in the future. What this balance looked like in practice however, was unique for each dyad given the differences in the types of facial differences and family structures, as well as their distinctive exchanges with the social, medical and media systems. Still, regardless of the method, each daughter believed that her mother was doing a good job, and each mother felt confident about the way they cared for their daughter.

Altogether, these results may suggest that there exists no right way of mothering a daughter living with a facial difference, or one correct model to promote and adopt. Mothers need not commit to *either* disconnecting from or safeguarding the daughter, but instead allow themselves to present in the gray area between the two. Thus, the results may serve to defend the notion of improvisational parenting: creating patterns and ways of fostering relationships that make sense and work for individual mothers and daughters, as well as the wider family unit. By revisioning the relationship as a fluid site of resistance that is negotiated and navigated by the members in the moment, all the while contending with a variety of social pressures, research of this kind can contribute to the emerging appreciation for diversity in scholarly work, and further support the movement away from pathologizing any one kind of relationship as dysfunctional, enmeshed, or overprotective. Consequently, fewer mothers will fall subject to the influences of mother-blame, and can instead feel supported and empowered in the relational work that they do with their girls, and daughters may begin to feel validated and secure in their connections with their mothers. Moreover, by applying this idea to the community of facial differences specifically, there emanates a potential for families touched by a variety of other physical differences and disabilities to be reconceptualised and understood in a new light.

### **Limitations & Areas for Future Research**

While the data resulting from the interviews with mothers and daughters was exceptionally rich and highlighted a number of key themes that were critical to answering the research questions, there were a number of limitations inherent within the study overall. One of the major limitations of the study was the difficulty in garnering certain responses from some of the daughters, particularly those in early adolescence. While mothers, and the older girls, provided extremely richness in their interviews, some of the younger participants were less aware of some of the roles mothers had played in their care and adolescence, and less able to reflect on some of the contributions that facial difference had made. As a result, it became complicated to include many quotations from their transcripts. Of course, this challenge is directly related to the developmental stage the young girls are at. According to the developmental literature, young people at the early stages of adolescence are less advanced cognitively, and are thus, less able to articulate complex ideas (Steinberg & Sheffield-Morris, 2001). From more of a critical perspective, the young girls are also too involved in more rapid changes to reflect on the ways their experiences have impacted their personal story and relationships overall. Including the voices of older daughters may provide additional insight into the experiences of daughters, and more completely address some of the research questions.

There was also a very small proportion of mothers who also had facial differences compared to those who did not. One of the specific research objectives of the project was to understand the ways in which a woman may mother differently when she too is living with a facial difference. The interviews with the three mothers with differences suggested there were more similarities than there were differences in their patterns of interaction with their daughters, but the sample of women included was still relatively small to make any type of formal

conclusion. As stated in both the results and discussion sections, the facial differences that these three women were living with were milder forms of their daughters' differences, and thus, facial difference did not play a large role in the way mothers felt they moved through the world. This may not be the case for a mother who, like her daughter, is living with a very noticeable difference. Garnering stories from more mothers who are living with a difference may point to ways of mothering differently that remain untapped at present.

This relates closely to the limitation involved with recruiting only from within the AboutFace database. Given its work as a national support and information network for individuals and families touched by facial differences, all members of AboutFace have access to a number of resources and programs that aid in navigating various developmental transitions and external systems such as education and health care. Thus, the mothers and daughters that elected to participate in the study were part of a well-connected and supportive community, and had been for a number of years. In fact, many of the mothers and daughters made reference to the ways in which AboutFace had made a significant positive impact on their lives. As such, the narratives from both the mothers and daughters were relatively positive, especially in conversations pertaining to their relationship. This however, may not be the case if other individuals with less social support were interviewed. Recruiting women through medical clinics and hospitals may have diversified the sample, and led to the development of different themes and inferences, given these individuals likely face a variety of social pressures and obstacles without the support of others with similar experiences. Future research should therefore look towards hearing their stories as well. Doing so may provide researchers with more insight into what familial relationships look like in the absence of groups like AboutFace, and potentially speak to the widespread need for similar communities.

There is also a need to balance the stories of daughters living with acquired and congenital facial differences. The sample for the present study was comprised of nine girls living with congenital differences and just one with an acquired difference. However, it is fair to assume that individuals and families touched by acquired differences may have unique stories than those touched by congenital differences given the diversity in adjustment processes. Many of the mothers interviewed spoke to a period of personal and familial adjustment when their daughter was born with a difference, but this was often a process that daughters were unaware of. Instead, many of the daughters with congenital differences made reference to their bodies and faces being the only ones they knew. Mothers similarly referenced their daughters' appearance as "just how she's always been" or "how she's always looked". This narrative diverged from the mother-daughter pair who frequently discussed the challenges associated with living life in one body or raising a child without a facial difference for a period of time, and subsequently having to integrate the difference into their sense of self and relationship. The differences in these stories highlight the fluidity and ever-changing nature of embodiment. Including more stories of acquired differences may provide a more complete understanding of the influence of facial difference on mothers and daughters as individuals, and its impact on their relationship. It may also make important contributions to the existing literature on facial differences and its effect on other familial dynamics and processes.

Gender is also an important consideration for future studies on facial difference. As demonstrated previously, social factors play an important role in the development and maintenance of a sense of self in adolescence, given that our current appearance culture values and reinforces beauty and body ideals (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). While males and females fall equally subject to these standards, the types of pressures differ based on gender. There exists increased for boys to conform to the masculine norms portrayed in

the media that emphasize certain physical and behavioural features, including physical toughness, emotional indifference, and independence (Stearns, 1990). Young men are also required to prove their masculinity by removing themselves from behaviours and interests considered “feminine” (Kimmel, 2000). While girls are said to be more embedded in the culture of appearance, boys are being similarly damaged by the communicated messages (Jones, Vigfusdottir, & Lee, 2004). In particular, where girls have been found to be more profoundly impacted by ideals in media, boys are more sensitive to criticism from peers around their body and selves (Jones et al., 2004). Moreover, the mother-adolescent son relationship has been found to be more distant and less intimate than the mother-adolescent daughter relationship, with boys being more likely to report feeling close to their fathers. Instead, mother-son intimacy is said to peak early on in adolescence and decrease with age, while mother-daughter intimacy is said to increase over the course of daughter’s development (Rice & Mulkeen, 1995). Consequently, the stories that arise from adolescent boys with living with facial differences may differ greatly from the narratives of adolescent girls, and the experiences of their relationship with their mothers may provide entirely different, yet meaningful results.

Finally, there are a number of other key individuals who are omitted from the study who inevitably play important roles in the participants’ family dynamics. Though mothers were the primary focus of the present investigation for a variety of reasons discussed previously, each of the twenty-two mothers and daughters made reference to other family members who were vital to their journey, including grandparents, siblings, extended family members and close friends. Future research should consider broadening their focus to include the examination of the experiences of these individuals, and their relationships with a child living with a facial difference, as a wealth of information remains to be uncovered and explored through hearing their stories. In preparing the literature review, only two studies were cited that studied these

alternative family members. Beresford (1994) highlighted grandparents as critical support systems in the family, supporting both the child and parents. Similarly, Benson, Gross and Kellum (1999) found that siblings also adjust to a sibling with a difference or disability, given they are sometimes made responsible for caring for their sibling, and occasionally deal with the depletion of parents' time and energy, jealousy and feelings of neglect. Broadening the focus of research to include other viewpoints can lead to a more complete and enriched understanding of how families are influenced by facial difference.

Fathers in particular, are key areas of future research however. According to Ball and Daly (2012), the exclusive focus on the maternal experience of child development communicates the idea that fathers' roles are negligible in the provision of care and emotional nurturance. This however, is not the case. In fact, Ball and Daly (2012) suggest that father's simply remain an "untapped resource" for the promotion of a child's optimal health and development given their exclusion from the majority of research. Having an "involved" father who is warm, sensitive, supportive, nurturing, affectionate, encouraging, and accepting is said to directly benefit the lives of children and their development, particularly in the areas of cognitive, emotional and social development (Allen, Daly, & Ball, 2012; Lamb, 2010; Pleck & Masciadrelli, 2004). Even more specifically, the role of the father has an important influence on the development of the daughter (Grimm-Wassil, 1994; Lamb, 1997; Morgan & Wilcoxon, 1998).

In research dealing with families touched by disability and differences, a similar trend exists: mothers and their experiences remain central, and perceptions and experiences of fathers often go ignored although they are profoundly impacted by their child's diagnosis and have qualitatively different experiences (Cashin, Small & Solberg, 2008; McNeill, 2004; Nicholas, Gearing, McNeill, Fung, Lucchetta & Selkirk, 2009). Families with a child with a disability

negotiate the task of parenting in unique ways (McNeill, Nicholas, Beaton, & Montgomery, 2008), and depending on how the parenting roles are divided within the marital dyad, the nature of a father's relationship with a child will vary from family to family. This was seen throughout a number of interviews with the women in the present study, whereby mothers clearly considered themselves part of a team or unit with their husbands through their frequent use of the term "we" when discussing their roles in their daughters lives. Fathers also have different courses of stress than mothers and make use of different adjustment and coping strategies after a child's diagnosis (Pelchat, Lefebvre, & Levert, 2007).

To date, only one study focused exclusively on fathers of children with facial differences. In this study, Klein, Pope and Tan (2010) interviewed nine fathers around their perspectives on parenting. Their results suggested that the majority of fathers (approximately 90%) felt optimistic about their child's future potential for happiness and success in life. However, this positivity did not cloud the fact that the majority still had some concern and worry about their child's future. All fathers also had a hand in supporting their child's peer relationships, and recognized their child's positive attributes. These results however are extremely basic, and provide only a small insight into the father-child relationship when the child is living with a facial difference. There remains little discussion of what aspirations or concerns individual fathers have, and there is not much development around the roles that fathers play in the lives of their children or the way the relationship is experienced by both fathers and children. As such, there still exists a large amount of research that needs to be done on the father-child relationship. Thus, studying fathers in a project similar to the one performed here may be a beneficial starting place for future research in the field.

## **Applications & Conclusions**

Despite its limitations however, the present study was vital to undertake. It is the first project to investigate from a critical, feminist, and contributonal perspective, the role of mothers in the lives of daughters with facial differences. It is one of the first studies to examine the implications of the girls' intersectional identities, and use qualitative methods that respect and value women's subjective experiences of living with or raising a child with a facial difference. Furthermore, the inclusion of mothers with and without facial differences provided an additional dimension of analysis that has yet to be explored in research within the community.

Unlike many of the previous studies on families touched by facial difference, the results demonstrate that the deficits and challenges noted by mothers are not inherent to having a child with a difference but rather, lie in the social barriers and pressures that mothers have to overcome along the way. The study also ascertains that mothers are far more in tune with their children than previous research suggests, and that the maternal relationships remain a critical source of strength, nurturance and resistance for young women. Lastly, it stands to defend the work of mothers and deconstruct some of the pervasive mother-blaming discourses by avoiding the prescription of specific parenting techniques or roles for mothers to adopt.

Moving beyond research however, the results of the present study are equally as important for use within communities that look to support individuals and families living with facial differences. The findings provide the foundation for reconceptualising and developing new resources that begin to reflect a better understanding of the roles that mothers play in their children's lives, and support them in their endeavors. They may also serve to aid organizations in helping women to recognize and shed some of their own internalizations of the mother-blame discourse. Finally, the results may allow for agencies and clinicians to acknowledge the

contributions that facial differences can potentially make to an individual's life and relationships, rather than exclusively preparing families for the ways it may take away from or interfere with their lives. Considering each of these implications, the present study serves to not only enrich the existing literature on facial differences overall, but shed light on new avenues for research in the future, and present alternative ways of thinking about and supporting individuals and families touched by facial difference.

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## Appendix A – Email Script for Participant Recruitment

### FEMALE PARTICIPANTS NEEDED FOR RESEARCH STUDY ON FACIAL DIFFERENCE & THE MOTHER-DAUGHTER RELATIONSHIP

My name is Victoria Pileggi and I am a second year Master's student at the University of Guelph in the Family Relationships and Human Development program. As part of my studies, I am conducting a research study under the supervision of Dr. Carla Rice. The proposed project, *My Mother, My Daughter, My Self: Mother-Daughter Relationships and the Influence of Facial Differences*, looks to fill in some of the gaps in the existing literature on facial difference, and looks to present an alternative means of understanding facial difference. Specifically, the project aims to explore the mother-daughter relationship when the daughter is living with a facial difference, a topic that remains previously unaddressed.

The specific objectives of the project include: exploring how mothers support their daughters in navigating social interactions, family adjustment, and encounters with the medical system; examining the ways in which mothers help their daughters transition through adolescence, and develop a sense of self, body and gender; understanding what facial differences can uniquely contribute to a girl's sense of self and the mother-daughter relationship; and analyzing the way in which a woman might mother differently when she too is living with a facial difference. The study looks to use focus groups for data collection to ensure that the individual voices of participants are heard and respected, and uncover the complex, often misrepresented, experiences of living with a facial difference or raising a child with a facial difference, particularly daughters.

If you are a young woman living with a facial difference (age 13-22) or are a mother of a daughter with a facial difference in this age range who is or is not personally living with a facial difference, I would like to invite you to participate in the study. You will have the choice of participating in either a one-on-one interview or a focus group. If you elect to participate in the focus group, please note that focus groups will be conducted to ensure participant comfort: one with daughters aged 13-15, one with daughters ages 16-19, and one with mothers living with or without a facial difference. The focus groups will take place in a private room at the University of Toronto over the course of one day, and each individual focus group will last approximately two hours in length. Breakfast will be provided at the beginning of the day and a token of appreciation will be provided to all participants at the end of each group. During the course of the focus group, you will be asked to respond to a series of predetermined questions, and engage with peers in open discussions on the topics addressed. One-on-one interviews will take place at a time and place that is convenient for you, and can be performed over telephone or Skype if you prefer.

Minimal psychological risk is possible due to the nature of the questions inherent within the study. You may be upset or made uncomfortable by the questions regarding your relationship with your mother or daughter and your experiences living with or raising a child with a facial

difference. The potential psychological risks however are no different than those that may be encountered on a daily basis, and it is my hope that by participating you may gain a deeper understanding of the ways in which your experiences have shaped your identity as a woman and mother, and impacted their relationship with their mother or daughter. The study may also serve to advance the literature on facial differences by valuing the unique experiences of individuals, using methods and theories that do not endorse the negative medical model of disability which has informed the majority of prior research in the field.

Your participation within the study is entirely voluntary. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. **Please note** that in using focus group methodology, it remains difficult to reliably remove all data from one speaker. Should you choose to withdraw from the study, every effort will be made to ensure as much of your data is removed from the transcript as possible. If you choose to participate in an interview however, and with withdraw from the study, your recording will be deleted, and there will be no record of your participation or responses. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so. Please note also that this study is in no way affiliated with AboutFace, and your membership to the AboutFace community will not be jeopardized in way should you decide not to participate or withdraw from the study at a later time.

**Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study.** For transcription purposes, focus groups will be digitally video and audio recorded, but the recordings will be transferred to an encrypted laptop and deleted from the recorder within 24 hours of interview completion. Should you prefer not to be video recorded, you can be situated outside the camera's field of view, so that only your voice is recorded. If you choose to participate in an interview, you will be audio recorded so that your responses can be reliably transcribed. **Please note** that to participate in the study, you must consent to either being audio or video recorded. Participants will have the right to review their transcript upon request. Any printed documentation or files with identifying information will be kept in a locked cabinet at the University of Guelph and shredded upon completion and submission of the dissertation for graduation. The electronic copies of the transcripts will be kept on the encrypted laptop for possible future use in a doctoral dissertation. If the project is submitted for publication, all participants will be notified via email, and transcripts will be kept until the final dissertation is accepted.

For more information regarding the study or if you would like to participate in the study, please contact me, Victoria Pileggi, at [vpileggi@uoguelph.ca](mailto:vpileggi@uoguelph.ca) or at (519) 824-4120 ext. 56987.

## **Appendix B- Consent form for Women**

### **CONSENT TO PARTICIPATE IN RESEARCH FOR WOMEN**

#### **My Mother, My Daughter, My Self: Mother-Daughter Relationships and the Influence of Facial Difference**

You are asked to participate in a research study conducted by Victoria Pileggi and Dr. Carla Rice, from the Department of Family Relations and Human Nutrition at the University of Guelph. This study is being undertaken as a thesis, in fulfillment of the requirements for completion of a Master's of Science degree in Family Relations and Human Development.

If you have any questions or concerns about the research, please feel free to contact the student investigator Victoria Pileggi at (416) 801-9693 or [vpileggi@uoguelph.ca](mailto:vpileggi@uoguelph.ca). Alternatively, you can contact the investigator's supervisor, Dr. Carla Rice at [carlar@uoguelph.ca](mailto:carlar@uoguelph.ca).

#### **PURPOSE OF THE STUDY**

The purpose of this study is to understand the mother-daughter relationship when the daughter is living with a facial difference from the perspectives of both women. It aims to explore how mothers support and offer guidance to their daughters through common experiences such as social interactions, family adjustment, and encounters with the medical system; examine the ways in which mothers help their daughters transition through adolescence, and develop a positive sense of self, body and gender; understand what facial differences can uniquely contribute to a girl's sense of self and the mother-daughter relationship; and analyze the way in which the role of a mother may differ when she too is living with a facial difference.

#### **PROCEDURES**

If you choose to volunteer to participate in this study, we would ask you to participate in either a focus group or a one-on-one interview. Four separate focus groups will be conducted in downtown Toronto: one for daughters age 13-16, one for daughters age 17-19, one for daughters age 20-22, and one for mothers. Focus groups will be held in a location that is private, transit accessible and ensures your comfort. One-on-one interviews can be conducted at a time and place that is convenient for you, or can be done via Skype or the telephone if you prefer. During the course of the focus group or interview, you will be asked to respond to a series of predetermined questions. In total, the expected time commitment required by you to participate in the focus group or interview is approximately an hour and a half to two hours. The expected completion date of the project is August 31, 2014. Should you desire to be informed of the results of this study, please contact the researcher by email and a copy of the final paper will be emailed to you.

#### **POTENTIAL RISKS AND DISCOMFORTS**

Minimal psychological risk is possible due to the nature of the questions inherent within the study. Participants may be upset or made uncomfortable by the questions regarding their relationship with their mother/daughter and their experiences living with/ raising a child with a

facial difference. The potential psychological risks however are no different than those that may be encountered on a daily basis. Minimal social risk is also possible, as the participants will be disclosing personal information with others present, and they may therefore feel a possible loss or invasion of privacy and be reluctant to answer questions.

### **POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY**

There are no direct benefits to the participants themselves, but they may gain a deeper understanding of the ways in which their experiences have shaped their identity as a woman and mother, and impacted their relationship with their mother/daughter. It may also serve to advance the literature on facial differences by valuing the subjective experiences of the individuals, using qualitative methods and using critical feminist and disability frameworks that do not endorse the medical, deficit model of disability which has informed the majority of prior research.

### **PAYMENT FOR PARTICIPATION**

While there is no monetary payment for participation within this study, all participants will be compensated with a gift card to Tim Horton's or Chapters Indigo as a token of appreciation for their time and commitment.

### **CONFIDENTIALITY**

**Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study.** This study is being conducted in partial fulfillment of the Masters of Science degree in Family Relations and Human Development at the University of Guelph. All participants will be referred to by an alias in the final report to protect their identities. Direct quotations from the focus groups and interview may be used within the final thesis report, however, all names and potentially identifying information will be changed. For transcription purposes, focus groups will be video and audio recorded so that speakers can be identified by the researcher, but the recordings will be transferred to an encrypted laptop and deleted from the recorder within 24 hours of interview completion. Should you choose not to be video recorded, please indicate this in the space below, and measures will be taken to ensure that you are removed from the camera's view, and that only your voice is recorded. One-on-one interviews will be audio recorded to ensure reliable transcription, and the audio recordings will be treated in the manner described for focus groups. **Please note** however, that to participate in the study, you must agree to be audio *or* video recorded. Participants have the right to review their transcript upon request. Any printed documentation or files with identifying information will be kept in a locked cabinet at the University of Guelph and shredded upon completion and submission of the dissertation for graduation. The electronic copies of the transcripts will be kept on the encrypted laptop for possible future use in a doctoral dissertation. If the project is submitted for publication, all participants will be notified via email, and transcripts will be kept until the final dissertation is accepted.

I agree to being video recorded in the focus group

I do not agree to being video recorded in the focus group, but do agree to being audio recorded   
only

## **PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. **Please note** that in using focus group methodology, it remains difficult to reliably remove all data from one speaker. Should you choose to withdraw from a focus group, every effort will be made to ensure as much of your data is removed from the transcript as possible. Should you elect to participate in an interview, your recording and responses will be deleted. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

## **RIGHTS OF RESEARCH PARTICIPANTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Director, Research Ethics	Telephone: (519) 824-4120, ext. 56606
University of Guelph	E-mail: sauld@uoguelph.ca
437 University Centre	Fax: (519) 821-5236
Guelph, ON N1G 2W1	

## **SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE**

I have read the information provided for the study “My Mother, My Daughter, My Self: Mother-Daughter Relationships and the Influence of Facial Difference” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

---

Name of Participant (please print)

---

Signature of Participant

---

Date

**SIGNATURE OF WITNESS**

---

Name of Witness (please print)

---

Signature of Witness

---

Date

## **Appendix C – Consent form for Youth**

### **CONSENT TO PARTICIPATE IN RESEARCH FOR YOUTH**

My Mother, My Daughter, My Self: Mother-Daughter Relationships and the Influence of Facial Difference

You are asked to participate in a research study conducted by Victoria Pileggi and Dr. Carla Rice, from the Department of Family Relations and Human Nutrition at the University of Guelph. This study is being undertaken as a thesis, in fulfillment of the requirements for completion of a Master's of Science degree in Family Relations and Human Development. If you have any questions or concerns about the research, please feel free to contact the student investigator Victoria Pileggi at (416) 801-9693 or [vpileggi@uoguelph.ca](mailto:vpileggi@uoguelph.ca). Alternatively, you can contact the investigator's supervisor, Dr. Carla Rice at [carlar@uoguelph.ca](mailto:carlar@uoguelph.ca).

#### **PURPOSE OF THE STUDY**

The purpose of this study is to understand the mother-daughter relationship when the daughter is living with a facial difference from the perspectives of both mothers and daughters. It aims to: explore how mothers help their daughters deal with common experiences in public, family settings and hospitals; examine the ways in which mothers help their daughters deal with adolescence; understand what facial differences can add to a girl's identity and the relationship with her mother; and analyze the way in which the role of a mother may differ when she too is living with a facial difference.

#### **PROCEDURES**

If you choose to volunteer to participate in this study, we would ask you to participate in a one-on-one interview or focus group in downtown Toronto. A focus group is a research method that involves a group of people being asked for their opinions, beliefs, attitudes and experiences. Questions are asked in a group and participants are able to talk with, ask questions of, and respond to one another. In this study, four separate focus groups will be conducted: one for daughters age 13-16, one for daughters age 17-19, one for daughters age 20-22, and one for mothers. Your focus group will be comprised of approximately four other girls around your age who are also members of AboutFace. Focus groups will be held in a location that is private, transit accessible and ensures your comfort. During the course of the focus group, you will be asked to respond to a series of questions, and engage with the other girls in open discussions on a number of topics. The interview can be conducted at a time and place that works for you, and can be done on the telephone or with Skype if you prefer. Participating in the interview means that you will also be asked to respond to series of questions, but will do so only in the presence of the researcher. In total, the expected time required by you to participate in the focus group or interview is approximately an hour and a half to two hours. The expected completion date of the project is August 31, 2014. Should you want to be informed of the results of this study, please contact the researcher by email and a copy of the final paper will be emailed to you.

#### **POTENTIAL RISKS AND DISCOMFORTS**

If you choose to participate in the study, please know that you may be made upset or uncomfortable when asked questions regarding your relationship with your mother and your experiences living with a facial difference. The risk of being made to feel this way however is no different than what you may encounter on a daily basis. Please note that you have the option to share personal information with others present, and you therefore may feel like some of your privacy has been lost or invaded and you may therefore be unsure about answering questions.

### **PAYMENT FOR PARTICIPATION**

While there is no money given for taking part in this study, all participants will be provided a gift card to Tim Horton's or Chapters Indigo as a token of appreciation for their time and commitment.

### **CONFIDENTIALITY**

**Every effort will be made to ensure that your identity is protected when you take part in this study.** All participants will be referred to by another name in the final report to protect their identities. Direct quotations from the focus groups or interview may be used within the final thesis report, however, all names and any information that may identify you will be changed. In order for the data from the focus groups to be written out and analyzed, the focus groups will be video and audio recorded so that speakers can be identified by the researcher, but the recordings will be transferred to secure laptop and deleted from the recorders within 24 hours of finishing the focus group. Should you choose not to be video recorded, please indicate this in the space below, and measures will be taken to ensure that you are removed from the camera's view, and that only your voice is recorded. Interviews will be audio-recorded to ensure transcription is done correctly, and these audio recording will be handled in the same manner described above. **Please note** however, that to participate in the study, you must agree to be audio *or* video recorded. Once the focus groups and interviews are typed out, you will get the chance to look back at what you said in the focus group if you'd like. Any files that are printed will be kept in a locked cabinet at the University of Guelph and shredded when the project is finished. Copies of the focus group and interview data will be kept on my computer for possible use in another research project. If this project is submitted for publication, you will be notified through email.

I agree to being video recorded in the focus group

I do not agree to being video recorded in the focus group, but do agree to being audio recorded only

### **PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you can stop taking part at any time without consequences of any kind. **Please note** that in using focus group methodology, it remains difficult to reliably remove all data from one speaker. Should you choose to withdraw from the study, every effort will be made to ensure as much of your data is removed from the transcript as possible. If you withdraw from an interview, your recording and typed responses will be deleted. You may also refuse to answer any questions you don't want to answer and still remain in the study.

**FOR PARENTS:****POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY**

There are no direct benefits to your daughter specifically, but she may gain a deeper understanding of the ways in which her experiences have shaped her identity as a young girl, and how her experiences of facial difference may have influenced her relationship with her mother. It may also serve to advance the literature on facial differences by valuing the subjective experiences of the individuals, using qualitative methods and using critical feminist and disability frameworks that do not endorse the medical, deficit model of disability which has informed the majority of prior research.

**RIGHTS OF RESEARCH PARTICIPANTS**

Your child may withdraw their consent at any time and discontinue participation without penalty. Neither you or they are waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your child's rights as a research participant, contact:

Director, Research Ethics	Telephone: (519) 824-4120, ext. 56606
University of Guelph	E-mail: sauld@uoguelph.ca
437 University Centre	Fax: (519) 821-5236
Guelph, ON N1G 2W1	

**SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE**

I have read the information provided for the study "My Mother, My Daughter, My Self: Mother-Daughter Relationships and the Influence of Facial Difference". All of my questions have been answered and I agree to take part in this study. I have been given a copy of this form.

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Name of Participant (please print)

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Signature of Parent

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Date

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Signature of Participant (Under the age of 18)

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Date

**SIGNATURE OF WITNESS**

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Name of Witness (please print)

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Signature of Witness

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Date

## Appendix D – Focus Group Probes for Daughters

1. Please briefly describe your current relationship with your mother.
  - a. What would you consider some of the highlights within your relationship?
  - b. What would you consider are some of the challenges of your relationship?
2. What role, if any, do you feel your mother played in helping you to navigate social interactions?
  - a. In what ways do you feel she was helpful or not so helpful in preparing you to handle these experiences?
3. What role, if any, do you feel your mother had in helping you enter and cope with the medical system?
  - a. In what ways do you feel she was helpful or not so helpful in preparing you to handle these experiences?
4. In what way do you feel your mother specifically has coped with or adjusted to your difference?
  - a. How did this make you feel?
5. What role do you feel your mother has played in helping the rest of your family to adjust or cope with your facial difference?
6. What do you feel is the most difficult part of being an adolescent?
7. What do you feel is the best part about being an adolescent?
8. In what ways do you feel your mom has supported you through your adolescence?
9. In what ways do you feel your mom has not supported you in your adolescence?
10. Does your mother share stories with you about her own childhood and adolescence?
  - a. What kinds of stories?
  - b. In what ways do you feel these stories have influenced you?
11. In what ways do you feel your mom has helped you develop who you are as a person?
12. In what ways do you feel your mom has helped you develop who you are as a woman?
13. In what ways do you feel your mom has influenced the way you feel about your body?
14. In what ways do you feel your mom has influenced the way you feel about dating or intimate/romantic relationships?
15. In what ways do you feel who you are has been influenced by your facial difference?
16. In what ways do you feel your facial difference has influenced your relationship with your mom?
17. What are your hopes for your future?
18. What are your hopes for the future of your relationship with your mother?
19. Aside from your mother, what relationships do you feel have acted as important sources of support?

### Appendix E – Focus Group Probes for Mothers

1. Please briefly describe your current relationship with your daughter.
  - a. What would you consider some of the highlights within your relationship?
  - b. What would you consider are some of the challenges within your relationship?
2. What role, if any, do you feel you have played in helping your daughter navigate social interactions?
  - a. In what ways do you feel you have been helpful or not so helpful in preparing her to handle these experiences?
3. What role, if any, do you feel you have played in helping your daughter enter and cope with the medical system?
  - a. In what ways do you feel you have been helpful or not so helpful in preparing her to handle these experiences?
4. In what way do you feel you have coped with or adjusted to your daughter's difference?
5. What role do you feel you have played in helping other members of your family adjust or cope with your daughter's facial difference?
6. What do you feel is the most difficult part about being a mother of an adolescent daughter?
7. What do you feel is the best part about being a mother of an adolescent daughter?
8. In what ways do you feel you have supported your daughter as she moves through adolescence?
9. In what ways do you feel you have perhaps not supported your daughter as she moves through adolescence?
10. Do you share stories with your daughter about your own childhood and adolescence?
  - a. What kinds of stories?
  - b. In what ways do you feel these stories have influenced your daughter?
11. In what ways do you feel you have helped your daughter develop who she is as a person?
12. In what ways do you feel you have helped your daughter develop who she is as a woman?
13. In what ways do you feel you have influenced the way your daughter feels about her body?
14. In what ways do you feel your have influenced the way your daughter feels about dating or romantic/intimate relationships?
15. In what ways do you feel your daughter's sense of who she is has been influenced by her facial difference?
16. In what ways do you feel who you are has been influenced by your daughter's facial difference?
17. In what ways do you feel facial difference has influenced your relationship with your daughter?
18. What are your hopes for your daughter's future?
19. What are your hopes for the future of your relationship with your daughter?

## Appendix F – Certificate of Ethics Approval

	<p><b>RESEARCH ETHICS BOARD – General</b></p> <p><b>REB-G</b></p> <p>Certification of Ethical Acceptability of Research Involving Human Participants</p>
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**APPROVAL PERIOD:** November 19, 2013 to November 19, 2014

**REB NUMBER:** 13OC039

**TYPE OF REVIEW:** Delegated Type 1

**RESPONSIBLE FACULTY:** Rice, Carla (carlar@uoguelph.ca)

**DEPARTMENT:** Family Relations & Applied Nutrition

**SPONSOR(S):** N/A

**TITLE OF PROJECT:** **My Mother, My Daughter, My Self: The Mother-Daughter Relationship and the Influence of Facial Difference**

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human subjects in the above-named research project and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement, 2<sup>nd</sup> Edition.

The REB requires that you adhere to the protocol as last reviewed and approved by the REB. The REB must approve any modifications before they can be implemented. If you wish to modify your research project, please complete the Change Request Form. If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Unexpected events and incidental findings must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Responsible Faculty, the safety of the participants, and the continuation of the protocol.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-council Policy Statement, 2<sup>nd</sup> Edition, requires that ongoing research be monitored by, at a minimum, a final report and, if the approval period is longer than one year, annual reports. Continued approval is contingent on timely submission of reports.

**Membership of the Research Ethics Board - General:** S. Banerjee, *Community Member*; J. Carson, *Community Member*; S. Chuang, *FRAN (alt)*; K. Chuong, *Graduate Student*; J. Clark, *PoliSci (alt)*; J. Dwyer, *FRAN*; M. Dwyer, *Legal*; B. Ferguson, *CME (alt)*; B. Giguere, *Psychology (alt)*; B. Gottlieb, *Psychology*; S. Henson, *OAC (alt)*; S. Hickson, *COA*; L. Kuczynski, *Chair*; A. Lauzon, *OAC*, R. Ragan, *Legal (alt)*; C. Rice, *FRAN*; V. Shalla, *SOAN (alt)*; R. Stansfield, *SOAN*; J. Wood, *Graduate Student (alt)*; S. Yi, *CME*.

Approved:

per

Chair, Research Ethics Board- General

Date: November 19, 2013