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Making space for positive constructions of the mother-child relationship : the voices of mothers of children with autism spectrum disorder

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MAKING SPACE FOR POSITIVE CONSTRUCTIONS OF THE MOTHER-CHILD
RELATIONSHIP: THE VOICES OF MOTHERS OF CHILDREN WITH AUTISM
SPECTRUM DISORDER

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By

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A Major Research Paper
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Master of Arts
in the Program of
Early Childhood Studies

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MAKING SPACE FOR POSITIVE CONSTRUCTIONS OF THE MOTHER-CHILD RELATIONSHIP: THE VOICES OF MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Unlike most research that employs attachment theory and ideologies of good mothering, this study takes a feminist theoretical perspective in order to explore positive aspects of the mother-child relationship, as described by mothers of children on the autism spectrum. Qualitative oral history interviews were conducted with five mothers of children diagnosed with ASD (autism spectrum disorder) in Toronto and the York Region of Ontario. Four themes emerged from the data analysis: building a bond through learning and growth of the self; "you will grow with them and your love will grow"; "find support where you can from people who will understand", and all I want is the best for my child's future. The findings from this study indicate that mothers of children on the autism spectrum can experience their mother-child relationship as a positive bond, one that develops as result of the mothers' self reflection and growth, which they in turn attribute to the influence of their children, and give this bond back to their children through their mothering practices. The findings of this research study help to make the case that the scope of intervention services must be broadened to focus on facilitating, and acknowledging the positive side of the mother-child relationship amongst families of children on the autism spectrum.

Keywords: autism spectrum disorder, mother-child relationship, bonding, ideologies of motherhood, attachment theory, oral history interviews

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In reviewing the literature on autism spectrum disorder (ASD), I soon realized there was minimal discussion of the mother-child relationship from the perspective of mothers. The following key questions came to mind in thinking about the literature: “how can we talk about the mother-child relationship without talking to mothers?”, “why would there not be positive aspects of being a mother to a child with ASD?”, “why have these mothers not been given a voice within the literature?”, and “why not encourage these mothers to actively engage in establishing a sense of closeness with their children?” I strongly believe this encouragement could benefit their overall experience as mothers, and possibly add to their well-being. There is a lot of discussion within the literature about how to support parents (e.g., mothers) of children on the autism spectrum. I think one of the ways is to recognize mothers as experts on their children, and to gain an understanding of their mother-child relationship, therefore, I felt in order to explore positive aspects about the mother-child relationship I needed to listen to the mothers themselves.

Within the scholarly literature, the relationship between a mother and a child on the autism spectrum is generally studied from a deficit perspective, with the perspective of mothers with typically developing children presented as normal and then compared to mothers of children with exceptionalities, whose relationships are seen to come up short. Attachment theory is often the basis for such comparisons, and is the leading discourse that constructs the mother-child relationship amongst mothers of children with exceptionalities.

For example, research findings often construct the mother-child attachment amongst children on the autism spectrum and their mothers as “difficult to develop” and “disorganized” (see Appendix I) (Naber, Swinkels, Buitelaar, Bakermans-Kranenburg, van Ijzendoorn, Dietz, van Daalen, & van Engeland, 2007; van Ijzendoorn, Rutgers, Bakermans-Kranenburg, van Daalen, Dietz, Buitelaar, Swinkels, Naber, & van Engeland, 2007; Watson, 1998; Wimpory, Hobson, Williams, & Nash, 2000). Similarly, within the literature where attachment is measured, based on separation and reunion between mother and child, generally attachment development in children with ASD is said to be minimal (Naber et al., 2007; Van Ijzendoorn et al., 2007; Watson, 1998; Wimpory et al., 2000).

Although another perspective does exist within these literatures, that children with ASD do demonstrate behaviors consistent with a secure attachment after separation and reunion with their mothers (Dissanayake & Crossley, 1996 & 1997; Howe, 2006; Rutgers, van Ijzendoorn, Bakermans-Kranenburg, & Swinkels, 2007). Most research studies have used the characteristics associated with ASD to substantiate the claim that children on the autism spectrum do not have the behaviors (e.g., limited social skills in reciprocity and communication) associated with establishing attachment bonds (Naber et al., 2007; van Ijzendoorn et al., 2007).

While attachment theory limits the understanding of the mother-child relationship, ideologies associated with motherhood in Western society establish standards that dictate expectations of what it is to be a good mother, and expectations of how mothers should interact with their children in developing a good mother-child relationship (Horwitz, 2007; Landsman, 1998; O'Reilly, 2004 & 2006; Rich, 1976). O'Reilly (2004) asserts that such ideologies disempower mothers when they do not follow the predetermined trajectory of being the "good or ideal" mother, e.g., mothering that is "24-7"; and the belief that the needs of the child always come before the needs of the mother. This experience of disempowerment is further compounded for mothers of children with ASD, as their experiences of being a mother and developing a relationship with their children are further scrutinized due to the nature of the child's exceptionality.

Given the predominance of the good mother ideology and the stronghold attachment theory has in psychological research on mother-child relationships, not surprisingly, mothers of children with ASD have been silenced within much of the scholarly literature, specifically in regard to discussing their mother-child relationship positively or otherwise. The silence of these mothers is further perpetuated in the literature when expert knowledge and quantitative data are presented as the only valid reflection of their mother-child relationship (Kingston, 2007).

Furthermore, the medical model, which through diagnostic assessments and treatments takes a scientific evidence-based perspective on illness and exceptionalities (Crow, 1996; Heslop & Williams, 2005), implicitly viewing an exceptionality as something that can be "cured or fixed", in order for the individual to experience the "norms" of society (Crow, 1996; Heslop & Williams, 2005). The implicit assumption for the experience of the mother-child relationship

then becomes that if we can "cure" or "fix" the child's exceptionality, only then can a mother-child relationship be developed.

The medical model is apparent within much of the literature on ASD, as mothers are often portrayed as stressed and depressed as a result of raising a child on the autism spectrum. For example, according to McKeever and Miller (2004) the literature portrays the coping strategies amongst mothers of children with exceptionalities as a maladaptive adjustment style (McKeever & Miller, 2004). As Green (2007) points out, "Pathologizing, and thus discouraging parental ability to find benefits in having a child with a disability is potentially very problematic for parents" (p. 151). Irrespective of the child's exceptionality, every parent (mother) deserves to feel connected with, and to see the value in their children, without their relationship being labeled as pathological.

Finally, the norms and standards within the ideology of motherhood when applied to mothers of children with exceptionalities demonstrate a process of normalizing the child's exceptionality and the experience of mothering. Through the concept of normalizing exceptionality, the individual is seen as different from the norm, and, therefore, should want to be made to fit into expectations of what is considered "normal" (Oliver, 1996). Within the medical model the qualities of the individual are not given recognition but rather ignored, by which diagnostic characteristics are used to frame the individuality of the person (Crow, 1996; Heslop & Williams, 2005).

Attachment theory, ideologies of motherhood, the medical model, and normalizing exceptionalities help to perpetuate a deficit perspective of a mother-child relationship, and serve to depersonalize mothers and their children with exceptionalities. However, as Howe (1995c) argues, all children are different and demonstrate personality and behavioral characteristics,

which influence maternal responses to the child, and the nature of attachment that develops between mother and child. Given this argument, irrespective of the child's diagnosis of ASD, I argue that mothers can feel a sense of closeness to their children, and can describe the nature of the mother-child relationship that exists between them and their children.

Theoretical perspective adopted for this study

In contrast to the deficit perspective taken in much of the literature on ASD and the mother-child relationship, the current research study takes a feminist theoretical perspective, and focuses on how mothers of children on the autism spectrum describe their mother-child relationship. Within the feminist literature scholars challenge dominant ideologies as they relate to women, and explore the experiences of women from their point of view (Horwitz, 2004; O'Reilly, 2006; Rich, 1976). Feminist scholars have been critical as to what and who defines women's experiences, and how such definitions undermine women's confidence as mothers (O'Reilly, 2006). According to Rich (1976), women's experiences as mothers have often been understood within the scope of an institution, rather than as an experience (Rich, 1976). Motherhood as an institution has developed circumstances for women that do not reflect their reality, but are so influential they end up shaping women's experiences as mothers (Rich, 1976). "Institutionalized motherhood demands of women maternal "instinct" rather than intelligence, selflessness rather than self-realization, relation to others rather than the creation of the self" (Rich, 1976, p.42). Motherhood lacks authenticity and agency, as women mother their children based on values found within the institution of motherhood (O'Reilly, 2004; Rich, 1976).

In order to move away from motherhood as an institution, and value the individual experiences of being a mother, feminist scholars suggest talking about women's experiences as *mothering*, rather than as motherhood (O'Reilly, 2004; Rich, 1976). Mothering as an experience

centers on mothers valuing and giving meaning to their experiences of raising their children (O'Reilly, 2004; Rich, 1976).

The feminist perspective acknowledges women's experiences as a facilitative factor toward their sense of empowerment (O'Reilly, 2006). Although the notion of empowered mothering is not clearly defined within the feminist literature, according to O'Reilly (2006) challenging ideologies of motherhood has "...destabilized the hold this discourse has on the meaning and practice of mothering and have cleared the space for the articulation of counter narratives of mothering" (p.45). By not having a definition of mothering, more space is created for diversity in the experience of being a mother. As a result, empowered mothering has at its foundation mothers validating their experiences, exercising their sense of agency and individuality, and realizing there is no right way to mother (Horwitz, 2004; O'Reilly, 2006). Thus, this approach is taken in this research study, in order to challenge dominant ideologies and narratives of motherhood, as they relate to mothers of children with exceptionalities, and to extend the knowledge base of qualities that are apart of the mother-child relationship.

Research Questions

This study employs a qualitative methodology, specifically the oral history interview and the use of thematic analysis, and is driven by the following research questions:

- 1) How do mothers of children with ASD describe the joys of their mother-child relationship?
- 2) What aspects of their mother-child relationship do they find most meaningful?
- 3) What have been the joys?

Mother-child relationship when ASD is a factor

What is ASD? ASDs are said to be a range of neuro-developmental disorders (e.g., autism, Asperger syndrome, pervasive developmental disorder-not otherwise specified) which impact the cognitive, linguistic, and social development of the child (Bowler, 2007). ASD runs along on a continuum in which specific behaviors appear more or less pronounced (Bowler, 2007). The diagnosis of an ASD is based on children demonstrating distinct behavior patterns in three main categories; social interaction (e.g., minimal social reciprocity), communication (e.g., limited language development), and behavioral patterns (e.g., repetitive behavior patterns with objects or mannerisms & minimal eye-to-eye gaze). Children with ASD have challenges specifically in the area of social and linguistic communication (Bowler, 2007).

What changes in the family when a child is diagnosed with ASD? The diagnosis of a child with ASD places stressful demands on families in regard to the financial and emotional impact, and process of accessing and negotiating intervention services for the child (Higgins, Bailey, & Pearce, 2005; Norton & Drew, 1994). Families of a child on the autism spectrum are raising their child under challenging circumstances, which may impact the nature of the mother-child relationship, but other than a focus on attachment theory, how and in what ways are not explicitly explored in the literature? Research findings indicate that feelings of sadness, loss, and guilt are predominant amongst mothers of children diagnosed on the autism spectrum (O'Brien, 2007; Olsson & Hwang, 2001; Sen & Yurtsever, 2007).

In 2007, Sen and Yurtsever conducted interviews with mothers of children on the autism spectrum and found mothers felt sadness due to the child's diagnosis of ASD. In addition to sadness, parents may also feel a sense of "ambiguous loss" related to no longer having the

"perfect" child and the expected parental role (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates., 2006; Landsman, 1998; O'Brien, 2007). Similarly, in another study which interviewed 63 mothers of children diagnosed with autism, the mothers expressed uncertainty in their role as mothers (O'Brien, 2007). As well, it is worth noting that the feeling of "ambiguous" loss is found to appear more prominent immediately following the diagnosis, suggesting that as time passes mothers receive more support and become more knowledgeable about their child's exceptionality (Norton & Drew, 1994).

Sadness and guilt impact parenting competency where parents may question their ability to handle challenging behaviors demonstrated by the child (Kuhn & Carter, 2006). In Kuhn's and Carter's (2006) study, amongst 171 mothers of children diagnosed on the autism spectrum, 21% of mothers felt their guilt impacted their abilities in parenting, and 80% said they did feel guilt when first informed about their child's diagnosis. However, the study did not indicate what aspects of their parenting abilities were impacted by their feelings of guilt, and what impact, if any, this had on the mother-child relationship.

Although findings from these research studies do not explicitly conclude that mothers of children with ASD never develop a positive mother-child relationship, there still exists an implicit assumption that mothers of children with ASD will continue to question their role as mothers, and have a different (i.e. worse) mothering experience that is not consistent with the "norms" of attachment between mother and child.

The stress associated with caring for a child with an exceptionality may impact the mother's ability to be responsive to the child, thereby negatively impacting development of the mother-child relationship (Howe, 2006). Children on the autism spectrum may demonstrate challenging and difficult behaviors (e.g., tantrums), which are variable, lack consistency and

patterning, causing parents to feel helpless in responding appropriately (O'Brien, 2007). Parents often have to concentrate on learning to manage these challenging behaviors through intervention services, (Singh, Lancioni, Winton, Singh, Curtis, Wahler, & McAleavey, 2007), with little emphasis placed on supporting the development of the mother-child relationship.

However, learning to manage these behaviors through intervention services may prove more problematic than helpful, because less focus may be given to supporting positive interactions between the mother and child. For example, in their 2007 study, Schwichtenberg and Poehlmann found the more hours of applied behavior analysis (ABA) parents were involved in, the more strain they experienced. Similarly, in interviews conducted with parents of children with developmental disabilities about behavior strategies, parents commented they suffered cognitive exhaustion on a daily basis "... because they were always thinking ahead about how they would handle their children's maladaptive behavior..." (Singh et al., 2007, p. 764).

Children on the autism spectrum do demonstrate difficulties with social and linguistic communication skills, which are factors attributed to developing bonds and relationships, this may have a significant impact on the psyche of parents, and their competency in parenting their child (Dale, Jahoda, & Knott, 2006; King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006; Kuhn & Carter, 2006; O'Brien, 2007). While the behavioral characteristics associated with ASD may impact the development of a positive mother-child relationship, Howe (2006) asserts that the development of the mother-child relationship may have nothing to do with the child's diagnosis of ASD per se, but more to do with the mother's state of mind.

King and colleagues (2006) conducted a study looking at belief systems amongst parents of children with exceptionalities. Through interviews with parents they found having hope was an important factor in perception of parenting ability. Hope allowed parents to create "...new

dreams to replace those initially felt to be lost" due to the child's diagnosis (King et al., 2006, p. 359). In addition, over time parents went through personal growth, in which they grew more patient, and felt greater unconditional love and acceptance for the child. More importantly, parents realized parenting was not about "fixing" or "curing" their child, but about accepting the child for who they are (King et al., 2006).

However, Kuhn and Carter (2006) assert that "Little is known about how cognitions among parents of children with an ASD may affect their parenting experience, and few assessment measures exist to investigate this area" (p. 565). In addition, within this body of literature on ASD, no connection is made between the emotional and social demands of raising a child on the autism spectrum in regard to how such feelings impact mother's perceptions of developing a relationship with their child. Compounded by this is the fact that research that has been done on the mother-child relationship amongst mothers of children with exceptionalities, much of it has used self-report measures, rather than the use of interviews to garner a better understanding (Beck, Daley, Hastings, & Stevenson, 2004; Gray, 2006; see Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Montes and Halterman, 2007; see Orsmond, Seltzer, Greenberg, Krauss, 2006).

The challenges associated with raising a child with ASD cannot be used to substantiate a claim that the experience of the mother-child relationship is doomed to failure, and only full of negativity. More recognition is needed that a positive mother-child relationship amongst children with ASD is possible, despite the unique challenges that mothers of children on the autism spectrum are faced with. In other words, if parental belief systems are focused on normalizing the child and on ideologies of motherhood, this creates potential for parents (mothers) to develop

a line of thinking that they cannot have a relationship with their child when their children's behaviors and their role appear inconsistent with those ideologies. Furthermore, "If parents of children with disabilities are repeatedly discouraged from finding and acknowledging the positive aspects of care giving, they may be denied the potentially positive consequences of doing so" (e.g., benefits to their emotional health) (Green, 2007, p.151) Therefore, it is important to support mothers of children on the autism spectrum to acknowledge that their experience of mothering is valid, and the child's diagnosis alone does not determine the nature of their mother-child relationship.

Attachment theory and ideologies of motherhood

"Typical" mother-child attachment. As explained at the outset of this paper, in the social science literature, the mother-child relationship is generally substantiated through attachment theory and (implicit) ideologies of motherhood, both of which establish interaction expectations for mothers and their children. Attachment theory describes attachment patterns that develop between a mother and her child (Ainsworth, Blehar, Waters, & Wall, 1978), and is based on mothers with typically developing children (Ainsworth & Marvin, 1994), and, therefore, has underlying assumptions about "normality" in regard to the mother-child relationship. Specific to the mother-child relationship, attachment theory discusses reciprocity between maternal and child behavioral characteristics as influential to the type and quality of attachment pattern that is developed (Ainsworth et al., 1978). For example, it is believed maternal sensitivity allows a mother to become attuned to, and respond to her child's emotional and behavioral cues, facilitating the development of a secure mother-child attachment bond (Ainsworth et al., 1978).

Even prior to having children, women are bombarded with ideological values associated with (good) motherhood (Landsman, 1998). The notion of becoming and being a mother is

socially constructed as an important aspect in a woman's life; constructed as her defining moment (Landsman, 1998; Shu, Lo, Lin, Hsieh, Li & Wu, 2006). Connected with this ideology is the expectation that mothers will develop a strong attachment bond with their children (Landsman, 1998; Shu et al., 2006). Such ideological values, as reflected in attachment theory, are a source of contention within the feminist literature, where ideologies of motherhood are critically challenged for their lack of validity in connection to the experiences of being a mother (Horwitz, 2004; O'reilly, 2006; Rich, 1976). However, when a woman has a child with an exceptionality these ideological values no longer apply; "...mothers of children with disabilities make their way within a society that devalues their children and in which their motherhood has 'failed' to follow the culturally appropriate trajectory" (Landsman, 1998, p. 77).

Ideologies of motherhood with an exceptional child. Mothers of children with exceptionalities often feel pressure to conform to a traditional view of motherhood (McKeever & Miller, 2004), and are directly impacted by such expectations. For example, in Nelson's (2002) research study that looked at the impact of a child's exceptionality on the mother, she found that when mothers were given the diagnosis of their child's exceptionality they felt they had to "negotiate a new kind of mothering," which included their mother-child relationship (p.520). More importantly the question remains as to why their experiences of mothering are called into question when their child has an exceptionality?

The idea of maternal sensitivity, found within attachment theory, holds mothers of children on the autism spectrum accountable for their children's development in the "good versus bad" mother ideology. The "good mother" ideology classifies maternal sensitivity as sacrificing the self for the child in order to meet the child's every need (Green, 2004; McKeever

& Miller, 2004). Therefore, a mother who demonstrates a secure attachment style with her child can be automatically categorized as the “good mother.”

The “bad mother” discourse has been perpetuated for mothers of children on the autism spectrum, with such terms as the “refrigerator mom” developed by Bruno Bettelheim during the 1960s (1967), which has pathologized their sense of motherhood (McKeever & Miller, 2004). The “refrigerator mom” terminology accused mothers of being unresponsive, lacking warmth and caring toward their children, as a result causing the development of autism in their children (Bettelheim, 1967; Kingston, 2007). Although the term no longer has merit, undoubtedly, remnants of such an ideology has caused “...silence, guilt, and pain among mothers of children with autism” (Kingston, 2007, p. 29). However, one must keep in mind that the notion of blame still exists today, as mothers “...are blamed as proximate causes if they do not make unrelenting efforts, paralleling “concerted cultivation,” to resolve” aspects of the child’s exceptionality (e.g., challenging behaviors) (Blum, 2007, p.202).

Due to such ideologies within the literature there is a strong emphasis on the diagnosis and the negative aspects of parenting a child with an exceptionality, positive attributes of the child with an exceptionality and their contribution to the family is readily ignored in the literature (Green, 2007; King et al., 2006). Specific topics on ASD which dominate the literature (e.g., depression, high stress levels amongst mothers) are portrayed as the only and standard experiences of parenting a child with ASD. The dominant representation of such literature limits the understanding of the mother-child relationship, forcing one to make assumptions about the nature of the mother-child relationship through a one sided view (e.g., the negative aspects of raising a child with ASD). As a result there is the potential for such literature to discourage mothers in finding positives within their mother-child relationship.

Each individual mother develops a relationship with her child, the quality and pattern of interaction will be different, irrespective of whether or not the child has an exceptionality. The applicability of attachment theory to children whose developmental trajectory is not based on normative development calls into question the validity of attachment theory on many levels. Attachment style classifications do not take into consideration the possible attachment patterns in children with ASD. For example, a mother’s indirect attachment may be seen through her involvement in advocacy work in establishing services for her child.

Furthermore, attachment theory is based on four different types of attachment categorizations (Howe, 1995b, see Appendix I), which are not enough to understand the dynamics of a relationship, especially amongst mothers of children on the autism spectrum. I would argue that attachment theory does not clearly demonstrate how an attachment style emerges into the specific qualities of the mother-child relationship. Relationships are complex, intertwined, and continuously evolving (Howe, 1995) to be captured or explained by a single theory. For mothers of children with exceptionalities the use of such categorization will further perpetuate the assumption that mothers of children on the autism spectrum cannot develop a mother-child relationship.

Measuring mother-child attachment

How is attachment measured in children with ASD? The standard procedure used to measure attachment is the Strange Situation Procedure (SSP) in which children are observed during mother-child separations and reunions to determine the nature of the child’s attachment response (Dissanayake & Crossley, 1997& 1996). The literature on attachment and ASD is limited, but that which exists demonstrates two contrasting perspectives; firstly, that the development of attachment between mothers and their children with ASD is minimal (Naber et

al., 2007; van Ijzendoorn et al., 2007; Watson, 1998; Wimpory et al., 2000), and secondly, that children with ASD can demonstrate behaviors consistent with attachment upon reunion with the mother in the SSP (Dissanayake & Crossley, 1996 & 1997; Howe, 2006; Rutgers et al., 2007).

Firstly, the behavioral characteristics of ASD have led to the implicit assumption that these children do not develop a secure attachment style with their primary care givers (Willemsen-Swinkels, Bakermans-Kranenburg, van Ijzendoorn, Buitelaar, van Ijzendoorn, & van Engeland, 2000). Researchers often categorize the attachment style of children on the autism spectrum as disorganized (Naber et al., 2007; Rutgers et al., 2007). Naber et al. and Rutgers et al. (2007) found children with ASD, tested using the strange situation procedure, demonstrated behaviors more consistent with a disorganized attachment style than a secure attachment style. Similarly, Watson (1998) found that free play between mothers and their child with ASD demonstrated limited joint attention and interaction compared to mothers of typically developing children. Researchers have suggested that the more severe the ASD the less likely a secure attachment could develop between mother and child, irrespective of maternal sensitivity or her effort to establish an attachment relationship (Naber et al., 2007; Rutgers et al., 2007). In these studies mothers demonstrated similar behavioral characteristics of mothers with typically developing children, in which the researchers argue support the evidence that severity of ASD plays a significant role in the development of an attachment (Naber et al., 2007; Rutgers et al., 2007; Watson, 1998).

Secondly, in their study of attachment, Dissanayake and Crossley (1997) found that amongst typically developing children, children with ASD and Down Syndrome, all demonstrated similar attachment styles after separation from and reunion with their mother's. Dissanayake and Crossley (1996) found that children with ASD maintained more proximity to

their mothers when the stranger was in the playroom, similar to children without ASD. Children with ASD who were verbal showed an increased intensity when reunited with their mothers, than children who were non-verbal (Dissanayake & Crossley, 1997). These studies demonstrate that children with ASD do demonstrate attachment behaviors toward their mother's (Dissanayake & Crossley, 1996 & 1997). Therefore, limitations in social behaviors amongst children with ASD can be attributed to the nature of the disability, and should not be considered "...a failure to construct a coherent strategy for organizing attachment behavior" between children with ASD and their mother's (Willemsen-Swinkels et al., 2000, p. 760).

What are the limitations of using the SSP to measure attachment in ASD? The Strange Situation Procedure (SSP) is an inappropriate measure of attachment for children on the autism spectrum, because of limitations in three key areas; behavioral characteristics associated with ASD, testing environment, and standards of normative development. Children with ASD generally benefit behaviorally from consistent routines and environments which the SSP disrupts by observing mother-child interaction in an unfamiliar environment (Norton & Drew, 1994; Rutgers et al., 2007). The possible "...stress caused by separations from the care giver and by the unforeseen sequence of various episodes in the strange situation procedure are problematic", because some children with ASD have difficulties when there are sudden changes in their environment (Rutgers et al., 2007, p.188). The contrived nature of a laboratory setting is unfamiliar, and may not capture the attachment behaviors that children on the autism spectrum do demonstrate in their natural environments (Rutgers et al., 2007).

With a limited focus on measuring attachment within a laboratory setting, using the SSP perpetuates the notion that children on the autism spectrum do not conform to the developmental patterns of normative attachment. According to Ainsworth and Marvin, "...many attachment

researchers have gone on to do research with the Strange Situation Procedure rather than looking at what happens in the home or in other natural settings..."(Ainsworth & Marvin, 1994, p. 12).

Research findings using the SSP has equated proximity the child demonstrates upon reunion with the mother to mother-child attachment, which simultaneously ignores how parents respond to the needs of their child and the nature of daily interaction between mother and child (Willemsen-Swinkels et al., 2000). Through the use of quantitative measurements of attachment amongst children on the autism spectrum, quality and depth of the mother-child relationship is lost, especially since attachment theory research is based on only four attachment styles (Howe, 1995b).

None of the studies reviewed did a comparison of the possible attachment behaviors the child demonstrated in the home, or other familiar environments to the child, or even asked mothers to describe the attachment they have with their child. Collecting maternal accounts would have added more to the knowledge about the mother-child relationship. In addition, no mention was made of time passed since receiving the diagnosis of ASD. This is an important factor because parents may continue to be in the process of learning how to respond to their child's needs in order to develop attachment with their child.

In all the literature normative forms of assessments were used, such that children with ASD continue to be consistently compared to typically developing children. Hoppes and Harris (1990) conducted a study of mothers with children diagnosed on the autism spectrum, mothers were given a questionnaire to measure how they felt about the interaction they had with their children. Nine out of ten mothers responded "yes" to the following questions –"Do you wish your child demonstrated more affection toward you?" and "Does your child's disability interfere

with his/her ability to be close and loving in his/her relationship with you?" (Hoppes & Harris, 1990, pp. 367-368).

Questions of this nature encompass negative ideological values of being a mother and view a child's exceptionality as an interference and inability to develop a relationship. The design of the questions had an underlying premise of normative attachment. When mothers answer these questions they are automatically forced to contrast their child as not typical in their ability to show affection and establish a relationship. In addition, there may be different facets of the exceptionality that may not interfere with the ability to develop a mother-child relationship or closeness, which would not be captured through assessments meant for typically developing children.

Moreover, using attachment theory to demonstrate the development of attachment of children diagnosed with ASD perpetuates a discourse of normalizing disability, meaning more emphasis is placed on trying to see how the child can fit into normative categories of attachment. The normalizing discourse implies children with exceptionalities are not accepted the way they are. This view is quite problematic in regard to the mother-child relationship because mothers may come to believe a mother-child relationship is only possible amongst typically developing children, or if their child demonstrates typical behaviors.

Furthermore, a normalizing discourse creates pressure for mothers to live up to a "standard" mother-child relationship, leading to guilt, rather than focusing on the unique qualities within her child to build and support their mother-child relationship. Mothers of children with exceptionalities may gain more out of their mothering experience by focusing on who their children are as people, and who they are as mothers. As O'Reilly (2004) states "...there

are other ways to mother, ways that do not deny a mother her agency, autonomy, authenticity, and authority, thereby allowing her both her selfhood and powers" (p. 11).

In order to measure attachment in children on the autism spectrum researchers must take into consideration the development of more appropriate attachment assessment tools, or other methods all together, such as individual interviews with mothers, or observation of children within their natural environments. Similar criticisms have been made in using the SSP amongst typically developing children, suggesting the SSP is not a representative measure of attachment in general (Clarke-Stewart, Goossens & Allhusen, 2001), and the validity of research findings need to be critically explored especially amongst children on the autism spectrum.

Furthermore, the entire construct of attachment possibly needs re-thinking as a means to explore and understand the nature of the mother-child relationship. There appears to be incongruency between the daily experiences of the mother-child relationship that can be explained by a child demonstrating a secure attachment. Perhaps the experience and development of the mother-child relationship is not solely about observing a child's reaction during separation and reunion with their mother, but more about the different ways relationship can be experienced, or the support networks that facilitate the experience of the mother-child relationship.

Indeed, I would go as far to make the claim that the current research findings on attachment theory and ASD are invalid, and should not be considered as an indication of the quality of the mother child relationship in children with ASD. This review of the literature demonstrates that research is needed that focuses on how mothers define and describe the relationship they have developed with their child.

Research on exceptionalities that takes into account the voices of mothers

The attachment literature does not represent the myriad of experiences amongst mothers and their children on the autism spectrum, as much of this research does not take into account the voices of mothers (e.g., through interviews). Many of the research studies understand the nature of the mother-child relationship through the use of self-report measures (Beck et al., 2004; Gray, 2006; see Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Montes and Halterman, 2007; see Orsmond, Seltzer, Greenberg, & Krauss, 2006).

Through self-report measures we have learned that mothers of children with exceptionalities do report the existence of a mother-child relationship, however with minimal understanding of the qualities that are apart of the relationship. For example, in a recent U.S. population based research study about maternal functioning amongst mothers of children on the autism spectrum, Montes and Halterman (2007) found that mothers reported having a close relationship with their child. In addition, mothers also reported to be coping very well with raising a child on the autism spectrum (Montes & Halterman, 2007). More importantly, Montes and Halterman (2007) argue that their findings call into question the validity of many research studies which claim that mothers do not cope well (e.g., worse) in parenting a child on the autism spectrum.

Another aspect of the mother-child relationship measured through self-report measures is expressed emotion. Beck, Daley, Hastings, and Stevenson, 2004, measured mother's expressed emotion towards their children with exceptionalities by asking mothers to describe the nature of their mother-child relationship within the last six months, for five minutes. Beck's and colleagues (2004) analysis of mothers five minute speech sample based on six categories, in which three categories took a negative perspective of the mother-child relationship. For example,

speech samples were coded for mothers "criticism – negative comments made by the mother about the child (coded as a frequency count), dissatisfaction – describes a child's unfavourable behaviours, characteristics, or personality traits" (Beck et al., 2004, p. 631). Their findings demonstrate that in comparison to their child without an exceptionality, "...mothers expressed more negative expressed emotion towards the child with..." an exceptionality (Beck et al., 2004, p. 634).

Problematic about their analysis is that it perpetuates a negative discourse about the mother-child relationship, if criticisms and dissatisfaction of the child are not explored in depth to determine the source of those feelings, our understanding of mother's expressed emotion toward their children becomes quite limited. Furthermore, through the use of self-report measures there are no further explanations for negative expressed emotion towards the child with an exceptionality.

Self-report measures as discussed in this section demonstrate a linear and predetermined focus on the mother-child relationship. According to Fisher and Goodley (2007) disability narratives are often forced to fit into a linear narrative model, which focus on diagnosis as a certainty through the lives of parents and their children with exceptionalities. The linear narrative model is rooted in the medical model, which creates narrow thinking about exceptionalities, and restricts the narratives of parents (of children with exceptionalities), rather than allowing a narrative construction which offer mothers a sense of agency (Fisher & Goodley, 2007).

There have been studies that have directly interviewed mothers about parenting a child on the autism spectrum (Gray, 2006; Woodgate, Ateah, & Secco, 2008). Although these studies do not directly deal with the mother-child relationship, they provide more detailed insight about parenting that may lend itself to understanding more about the mother-child relationship amongst

mothers of children diagnosed on the autism spectrum. For example, in his longitudinal study, Gray (2006) conducted in-depth interviews with parents (nineteen mothers) about how they have coped with their child's diagnosis through the years. His findings demonstrate that over time parents relied on emotion focused coping styles, in which they focused and appreciated the positive qualities within their children (Gray, 2006). Maternal focus on the positive aspects of the child may contribute to how mothers experience the mother-child relationship as their interaction with the child is through a positive outlook.

A positive outlook may allow mothers to view their role in their children's lives as an important aspect of their mothering experiences. In a Canadian study which explored the experiences of mothers raising children with exceptionalities, Panitch (2007) reveals how their role as "accidental activists" have become an important aspect of their mothering experiences. Demonstrating that through this role, these mothers have found a voice for themselves and their children, however, Panitch's (2007) work does not specifically focus on advocacy work amongst mothers of children with ASD, which warrants the need for this research study.

In their research study, which analyzed narratives about mothers experiences with health professionals and their children with exceptionalities, Fisher and Goodley (2007) found narratives that demonstrated the child (not their diagnostic label), and narratives that were created as one journey's through their experiences, allowed more opportunities for discovering beauty and insight in their situation. Furthermore, both types of narrative constructions were more empowering to mothers in the research study because they felt a sense of agency (Fisher & Goodley, 2007). The empowerment comes from mother's ability to construct and validate their narratives based on their experiences, and not predetermined outcomes within a medical model

perspective, which is prescriptive toward children with disabilities and their futures (Fisher & Goodley, 2007).

As is discussed in the following section, this study employs interviews in order to better capture the experience and depth of the mother-child relationship as described by mothers of children on the autism spectrum.

Methodology

Methodological approach and rationale

Psychological researchers who study ASD and the mother-child relationship rely on observations (e.g., strange situation procedure) in order to measure mother-child attachment amongst mothers of children on the autism spectrum (Dissanayake & Crossley, 1996 & 1997; Naber et al., 2007; van Ijzendoorn et al., 2007; Watson, 1998; Wimpory et al., 2000). This research generally reports that a child with ASD has difficulties in demonstrating a secure attachment style with her/his mother (Naber et al., 2007; van Ijzendoorn et al., 2007; Watson, 1998; Wimpory et al., 2000).

One of the major limitations of an observational research strategy is that it provides only descriptive data (Babbie & Benaquisto, 2002). Thus, this current body of research on ASD and the mother-child relationship has not considered the maternal voice as a way of understanding mother-child interactions, likely because in the discipline of psychology, such research would not be considered “objective” or valid. When maternal voices have been taken into consideration, the focus is primarily on the stress and emotional factors related to raising a child with ASD (Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Olsson & Hwang, 2001; Sen & Yurtsever, 2007; see Hastings, Kovshoff, Ward, delgi Espinosa, Brown, & Remington, 2005). In addition to relying only on observational strategies, these research studies are grounded in attachment theory, which quantifies the mother-child attachment into four categories (Ainsworth & Marvin, 1994), while simultaneously disregarding the depth and dynamic processes involved in the mother-child relationship amongst children diagnosed on the autism spectrum.

In order to add a new dimension to research on ASD and the mother-child relationship, the current research study uses a qualitative approach to data collection and analysis. A qualitative approach allows researchers to gain in-depth knowledge about specific subjective human experiences in regards to a *how* based inquiry (Elliott, 2005; Josselson & Lieblich, 2002). Consistent with a qualitative approach, this research study was interested in finding out *how mothers of children with ASD describe their mother-child relationship?*

The qualitative approach taken in this study is consistent with the social constructivist and post-modernist stance that individuals construct their realities (Hale, 1995; Cheung, 1997). In other words, the interactions and meanings assigned to those interactions are considered social constructions made by the individual (Cheung, 1997). Thus, in keeping with this perspective, it is argued here that the implicit assumption in the literature about the disorganized and non-existent mother-child relationship is a construction that serves to create a particular reality of the mother-child relationship for mothers of children with ASD. The use of a qualitative approach, situated within a constructivist paradigm, can generate new concepts about ASD and the mother-child relationship that has not been explored through previous research studies.

Research strategy and rationale

The particular strategy used in the current qualitative study is oral history. Oral history is a research tool that guides a researcher's approach to interview questions. The goal is to have participants share their memories about past experiences, which presents itself in a narrative form (Babbie & Benaquisto, 2002b; Creswell, 2007). Oral history allows for an in-depth collection of qualitative data that accesses "...silenced or excluded knowledge, for unearthing and preserving this "missing" knowledge within the scholarly research context (Leavy, 2007, p. 154).

Thus, an oral history approach to data gathering provides space for exploring the positive aspects of the mother-child relationship as described by mothers of children with ASD.

Selection of participants

In determining whom I would seek as potential participants in this study, I was guided by an evaluative research study on parental involvement in an ASD intervention programme for preschool children, Whitaker (2002, p. 418) found that when "...there was only a short interval between diagnosis and participation in the workshops, parents were not always emotionally ready to either process all the information provided or apply it to their children (even when an approach was of direct and immediate relevance)". Therefore, I chose not to include mothers of a child recently diagnosed with ASD, as they may not have wanted to discuss their mother-child relationship.

However, the literature has demonstrated that coping with the diagnosis of ASD runs on a continuum; initially the diagnosis of ASD has an emotional impact but as time passes parents are better able to cope with the diagnosis through coping strategies and the use of social supports (Gray, 2002 & 2006; Tway, Connolly, & Novak, 2007). In addition, with time research has shown that parents are better able to manage the child's behaviour, understand the nature of the diagnosis, have readjusted their beliefs over time about the child and their parenting role, and recognize the positive aspects of the child (King et al., 2006). Based on these research findings, which were done over a 1 and 10 year period (King, et al., 2006), mothers who were in the five to ten years post the diagnosis period were sought for this research study.

The research study was conducted in Toronto and York Region, of Ontario. The topic of inquiry had the potential to be sensitive in nature, and according to Babbie and Benaquisto (2002b) a smaller sample size is advised when dealing with a topic that "...is complex and

requires coverage of a large number of issues", or that "...is emotionally charged or controversial". Taking these factors into consideration the sample size of the research study was capped at five mothers.

Recruitment

Upon approval from the Research Ethics Board (REB) at Ryerson University, a purposeful sampling strategy was employed in order to recruit participants for this study. Recruitment occurred at twelve agencies that specifically provide services for families and children with developmental exceptionalities (e.g., ASD), four community centres, and one childcare centre. I contacted the managers and was granted permission to advertise the research study via a flyer on their information boards (e.g., agency website or bulletin board at the agency). The flyer included the following information; contact information of research investigators, description of the study, type of compensation, and potential benefits of the research study (see Appendix II). Research participants made contact with the researcher either through telephone or e-mail.

Participants

Three of the five women were single mothers, and two were married. The mothers ranged in age from early 40s to early 50s. All the mothers were Caucasian (although from diverse backgrounds). Four out of the five mothers had sons (one of whom was a step-mother), and one mother had a daughter. Except for one mother, all the other mothers had additional children. The age of the children (with ASD) ranged in age from fifteen to twenty years of age. The age range of diagnosis was between three to five years of age for four mothers, and twelve years of age for one mother. Within the autism spectrum, two children were diagnosed with PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified), one with autism, and two children

with Asperger's Syndrome. Four out of the five mothers described their children as having moderate to high language skills.

Data collection

As stated previously, the data collection tool used in the study was oral history interviewing, which engaged the research participants in a process of discussing past memories of their mother-child relationship from the time their child was born. Such an approach generally involves a 'natural flowing' conversation, which gives participants the room to tell stories about their mother-child relationship without a predetermined chronological approach to asking questions (Babbie & Benaquisto, 2002b). At the same time, a list of general questions was developed to serve as a general guideline for conducting the interview, in order to explore and build upon what had been said, and to demonstrate the goal and direction of the interview (see Appendix III).

The strengths of using an oral history method allowed participants to guide the focus and direction of their narrative (Babbie & Benaquisto, 2002b; Reinhartz, 1992). In keeping with the focus of the research question it was important that the mothers were given the opportunity to guide the narrative, as a result the interviewer limited the use of interruptions, and asked clarification questions when deemed appropriate. In addition, to demonstrate support and understanding of the narrative accounts the use of "uh huhs," head nods, and eye contact were used. As discussed by Babbie and Benaquisto (2002b), the researcher must take the role as an active listener, and employ the use of the following questions based on participant narratives, "how is that?, in what ways?, how do you mean that? ,what would be an example of that ?" each of which were employed where necessary during the interview.

Procedure

The interviews took place over a three-week period; three interviews took place at Ryerson University, and two at a community agency in a private space. The interview began with the following question by the principal researcher (Natalia Charles): "I am interested in looking at the development of the mother-child relationship of mothers with children diagnosed with autism. I am interested in hearing positive stories about the experiences up to today that have shaped / influenced your mother-child relationship?" The interviews were recorded, and lasted between forty-five minutes to one hour. Recording the narratives meant the data was captured more accurately, and when transcribed represented more exactly the narratives of the mothers, than if hand written notes had been used.

In keeping with the feminist research practice, the transcribed interviews and direct quotes that appear in the final paper represent the words as spoken by the participants, in order to "...familiarize readers with the [women] who were studied and enable the reader to "hear" what the researcher heard" about the experience of the mother-child relationship (Reinharz, 1992, p. 39).

Participants were compensated with twenty dollars in cash in order to cover their transportation costs, either through the use of public transit or parking when travelling to Ryerson University or to the agency. The value of the compensation was developed based on cost of transportation (public transit and parking). In addition mothers that chose to do member checking were compensated with a five dollar gift card.

Ethical considerations. Ethical standards were maintained throughout the process of conducting the research study. In keeping with ethical guidelines and requirements of the REB, a consent form was developed, and was signed by each individual prior to participation in the research study (see Appendix IV).

The literature has shown that parents of children with ASD experience strong emotions in relation to the child's diagnosis (Beck, Daley, Hastings, & Stevenson, 2004; Olsson & Hwang, 2001; Sen & Yurtsever, 2007), therefore, discussing the mother-child relationship had the potential to trigger emotional memories for the research participants. To ensure mothers had the necessary supports, if the discussion became emotional, a list of services within the community was provided if participants needed to speak to a professional (see Appendix V). As the researcher I was bound by ethical regulations to maintain confidentiality of information provided by research participants, therefore, no names or identifying characteristics are presented.

Data organization

Narratives from each of the interviews were transcribed, and stored in a computer file (e.g., word document). All data was securely stored; computer data (e.g., recorded audio files of interviews, transcribed data) was saved within a separate password protected account created specifically for the research study, and hard copy documents (e.g., consent forms) was stored in a folder for each participant and stored in a locked drawer, in both cases the information was only accessible to the principal researcher. In addition, codes were used to link data to participants during data analysis, within the body of the research paper pseudonyms are used.

All data, including audio files (which will be erased from computer and placed on a memory stick), consent forms, and transcriptions are stored in a locked filing cabinet, and after one year from the completion date of the research study all data will be discarded. Audio files will be deleted, and hard copy documents will be shredded.

Data analysis

The data were analyzed using a thematic analysis (Cresswell, 2005) via NVivo, a qualitative software program that allows the researcher to organize and categorize the data based on developing themes and concepts. More specifically, the following data analysis strategy was used for each individual interview (Chase, 2002; Neuman, 2006): (a) each transcription was read over several times, as well as listening to the audio recording of the interview, and labels were assigned to parts (words, sentences, phrases) of the narratives; (b) the codes were then organized into categories based on similarities (e.g., self-growth); (c) a definition/explanation was established for each category in relation to the content and themes of the data; (d) and lastly, specific excerpts from each transcription was assigned to a category to further substantiate the meaning. The themes and concepts that emerged from each individual's interview was cross checked within other interviews and were further categorized to determine overarching themes of all the data collected. Interpretive comments in the discussion were developed based on cross references with the current literature, and with the context of participants' narratives.

Trustworthiness of the data

In the context of social constructionist and post-modern social science, the notion of one "truth" consistently being found in the same context by the same, or different individuals can no longer be the leading underlying assumption when discussing validity in qualitative research of people's lived experiences (Dockett & Perry, 2007). When conducting research about an

individual's lived experiences, the only truth that exists is the person's experience in that particular context, and their construction of their experiences (Dockett & Perry, 2007). Even so, there are key steps a researcher can include in their research design that strengthens the trustworthiness of the data collected (Dockett & Perry, 2007; Morrow, 2005). The following strategies were used in this study to strengthen its trustworthiness:

1) The use of an oral history approach ensures mother's construction of their mother-child relationship is represented through their voice, rather than through the lens of structured surveys or interviews (Elliott, 2005). While some may argue that narratives are not a true representation of the "truth", or that it is not "...closely related to those that would occur spontaneously in conversation and other aspects of daily life" (Elliott, 2005). As argued previously, stories are socially constructed, and people engage in specific storytelling of life events within various contexts and situations, and as a result no single version of a story ever exists (Linde, 1993; as cited in Elliott, 2005). The narratives provided about the mother-child relationship can be considered a trustworthy construction within the context of the research study.

2) There are specific topics that people may have never discussed or formed as a narrative (Elliott, 2005). Due to the design of the research study, which required mothers to engage in a narrative construction of their mother-child relationship, this may have been the first time mothers were asked to describe their mother-child relationship in this manner (Elliott, 2005). In addition, "... the meaning and understandings that the individuals attach to their experiences are not necessarily pre-formed and available for collection, rather the task of making sense of [their] experiences will be an intrinsic part of the research process" (Elliott, 2005). Therefore, it is most likely that by participating in the research study this was the first time mothers gave meaning to

the positive aspects of the mother-child relationship, and thus can be considered a valid and trustworthy representation of the mother-child relationship.

3) The validity of the research data coincides with the nature of the research question, such that if the research question is to explore an individual's experiences, their accounts can be considered to be valid (Elliott, 2005). As stated earlier, the research question is "How do mothers of children describe their mother-child relationship of children diagnosed with ASD?" This research question is clearly about mothers' experiences, and therefore, their accounts must be considered valid.

4) Member checking interpretations of research findings with participants have been described as increasing validity in qualitative research designs (Dockett & Perry, 2007; Morrow, 2005). In addition, themes and interpretations provided with examples of participant's narratives also establish the interpretations as more credible (Morrow, 2005), which has been employed in this paper. In this research study participants were given the option to do member checking, in which three mothers reviewed their transcribed interview and direct quotes, and agreed for them to appear in this research paper.

Findings

The findings presented in this study seek to represent the mother-child relationship as it has been experienced, including up to the point of the research study. In this study no operational definition of a "mother-child relationship" is offered. Rather, it is constructed by the mothers in their narratives of their lived experiences of mothering a child on the autism spectrum. This section describes the nature of the mother-child relationship within four themes which emerged through thematic analysis of the data (see table 1).

The four themes are:

- 1) Building a bond through learning and growth of the self;
- 2) "You will grow with them and your love will grow";
- 3) "Find support where you can from people who will understand"; and
- 4) All I want is the best for my child's future.

Table 1. *Themes and sub-themes of the mother-child relationship*

Building a bond through learning and growth of the self
"I have found things in me that I didn't know where there"
"What is being a parent of a child with ASD, it gives you a voice"
"I always encourage my kids"
"You will grow with them and your love will grow"
"Everyday more love"
"Lots of joys"
"Everybody likes to feel their children are valued in the world"
A positive outlook
"Find support where you can from people who will understand"
Formal support systems
Find the balance; "I know if I feel good that's going to impart to my child"
All I want is the best for my child's future
Your child is not invited
"You are now telling me I have to live forever"

1. Building a bond through learning and growth of the self

Within the narrative accounts, self-growth and learning was expressed as a positive aspect of the mother-child relationship. The mothers described growth and learning as enabling them to discover aspects of the self they never knew they had, which in turn contributes positively to their role as mothers and to the relationship they have with their children. The theme of learning and self-growth was demonstrated in three specific areas: a) "I have found things in me that I didn't know were there", b) "what is being a parent of a child with ASD, it gives you a voice", and c) "I always encourage my kids."

I have found things in me that I didn't know were there. The mothers narrated about the growth and learning of the self they experienced as a result of having a child with ASD. The mothers described self growth and learning as a positive journey of self discovery that may not have happened if it was not for their children. Some mothers specifically discussed their growth as positively contributing to their mother-child relationship, because they now had the skills needed to support their children's development. Amy (a pseudonym) a mother of a sixteen-year-old daughter, explores the deep sense of love her daughter Crystal (pseudonym) has taught her about, and how that has been a part of their mother-child relationship that she continues to develop with her daughter:

Amy: I think she's [daughter Crystal] just taught me how to love, really like a deep kind of love that is very different than a man and woman love, or you know, and its made me appreciate my own mother a lot more just being a mother, and taught me, you know our relationship is good, we work at it, we think about it, and [I] try to do the best for her.... So basically in terms of positives for me and Crystal, well certainly for me, I have grown to be a better mother with her, I have found things in me that I didn't know were there.

Researcher: like what?

Amy: How can I describe it, well I learned to be assertive. (Amy, mother of Crystal)

Laura discusses her self-growth and how it is reflected in her outlook about being a mother to a child with ASD:

I learned that we should accept people for who they are and not what we think they should be. We need to celebrate our children for who they are, regardless of a diagnosis. We need to honour what is success for them, not necessarily what society's idea of success is. We can't assume that every individual with autism wants a bunch of friends, Sean does, but there are some individuals with autism who are content within themselves or having a few close people around them. I have learned that it is important to take the child's lead. In most cases, a child with autism will show strength in a particular area. It is important to develop those strengths, as later in the child's life that strength may help them be more successfully employed. (Laura, mother of Sean)

One mother specifically describes the transformation she has gone through, in which she highlights the self before and after becoming a mother to a child with an exceptionality, and how such a transformation has allowed her to recognize and appreciate qualities within her son:

If I could describe how Sean has helped me in one sentence, I would say that he taught me to be a better person, a bigger person, a more expanded person, to look outside the box, and not to judge. For instance, Sean may act out in a store and I will see people turning around and looking at me. Their faces seem to say "your big kid sure is a brat." I understand their reaction because I used to think like that and have my judgements. Now when I look at a parent whose child or adolescent is having a tantrum and I think "Oh man, that's really tough. I bet that kid is having a hard time. If he is acting out in public, how is he acting at home?" Parenting Sean has built compassion within me and helped me to realize that all is not what it appears to be. Being a parent of a child with autism has stopped me from being so judgemental. I am learning to recognize that everyone has something to contribute, and I am really grateful that Sean has so many wonderful qualities. (Laura, mother of Sean)

Other mothers also describe their self-growth and learning:

Having my child be she you know special needs or not, made me grow as a person, totally, I was very you know more insecure, I was sort of shy, I didn't ummm, I was self centered because I only had me. (Amy, mother of Crystal)

You know sure I am a different person than I would have been, I am sure I am a lot more flexible and understanding...and things like that. (Lisa, mother of Matthew)

And just grow with your child because I think that's what it is, you're growing into being a mother with a special needs child while they're growing, and so it's not everything at once. (Amy, mother of Crystal)

"What is being a parent of a child with autism, it gives you a voice". Within the narratives becoming an advocate for the child was a prominent sub-theme of *building a bond through learning and growth of the self*. Learning to be an advocate for their children stemmed from being attuned to their children needs. The mothers discussed how finding their voice allowed them to speak up for their children in accessing services, and ensuring their children was treated fairly. In addition, they expressed their role as an advocate in ways that demonstrated they were defenders for their children. Part of the growth for some of these mothers was finding a voice they never knew they had, feeling a sense of empowerment, and being grateful that their children had brought this into their lives. The learning and growth that took place for these mothers made them feel more connected to their children, because their children were able to allow them to grow into the mothers they are today who can support and be proud of their children:

...I remember one time in a supermarket some lady telling me off because my child was spoiled rotten, I said "I guess you didn't realize he has autism" and she still didn't look very happy, and I said "that means that he has trouble controlling his behaviour," I said "I am hoping he will improve with age", I didn't want to add "I am hoping you'll improve with age!".... (Lisa, mother of Matthew)

Trust your instinct, I was never sure, but once I felt that control, and even the most knowledgeable person with degrees can sit across from me, but I still know this is my child, and I appreciate what they are saying, but I have had people you know in big school meetings, one lady, "well I think we should think about putting her here and there," and I thought I am not changing her, like she is happy here, why would I", you know, but realizing that I had that I said "no, that is not even something I want to discuss". So learning your power....because like any mother, whether it be special needs mother or not, you really become their defender, you know, you just become a different person, you really grow. (Amy, mother of Crystal)

Laura: Having a child with autism has given me a voice, it has given me courage, and I have learned that things I would not necessarily fight for myself, I will fight for my child. It is like being a mother bear...as an individual you might put up with a whole lot, but when it comes to your child and what they need and are entitled to...

Researcher: you know they deserve it

Laura: Yes, I think it is really important to give support to those parents who don't know their child's rights and how to advocate for them. (Laura, mother of Sean)

I remember being in first early meetings, with like a school representative, two people from the school board, the psych this, the psychologist here, and thinking "oh my god", you know, and not knowing my power at that point, feeling like they could take my child or put her anywhere. But then one day one of the social workers said to me, "you know it is really up to you, no one can do anything without you", and I thought...., and then I felt better, because I think I didn't feel that control, I wasn't sure what my control was". (Amy, mother of Crystal)

Irene describes the importance of advocacy in regard to her son's future:

...and I think, you know, I have been a big advocate, because I think it is important that we get the help for him and get help for other children... Joseph is a good kid and he will grow up to be a good kid, and probably a good husband!Joseph would go to the nth degree, and he will go far, and he will be fine. (Irene, mother of Joseph).

As one mother specifically highlights the journey of finding her voice for herself and her son, demonstrating how the use of her voice is directly connected to her child:

Sean was a new student to the school, and none of the teachers knew how to teach a child with autism. So administration and teachers would imply "He doesn't belong here. Sean belongs in a segregated classroom, in a segregated school." It was difficult and challenging to become an advocate and insist that Sean belonged in a regular classroom with his peers. Even though Sean is only 16 years old, it was a relatively new idea to include a child with autism in a regular classroom. Sean was the first and only child in any of his grades, and for many of his teachers he was the first student with autism they had ever taught. So Sean has been a pioneer, and I had to become an advocate and fight every year to get a teaching assistant, fight to have him included in his community school. One of the best pieces of advice I received was from a principal at an inclusive school who believed all children should be welcomed and included. He said to me "You're welcome to bring Sean to our school Laura, but I believe Sean belongs in his own neighbourhood," and he went on to say "you need to learn to speak for Sean until Sean can speak for himself." That sentence became my mantra. I would ask myself "what would Sean want me to say to the people who make decisions as to where he should go to school?" I believed Sean would want me to say "I want to be welcomed in my home school; I want to be where my sister and step sister attend school. I want to be in the community where I live and where the kids on my street will know who I am. I don't want to be bussed to some special school. I want to be treated like everybody else." (Laura, mother of Sean)

For Laura, the desire to be an advocate was always within her, but as a result of having a child with ASD her inner voice to speak up for the needs of her child was strengthened and reinforced. She discusses her advocacy as not only an experience of growth for herself, but something she wants for her son, so that he too can learn to defend himself. Laura really captures the metamorphosis mothers go through in becoming an advocate for their children:

...I remember thinking, even as a young girl, that it is not fair that anybody is marginalized for being different. As young as grade 4, I enjoyed public speaking. I liked the idea of giving a voice to those who, for whatever reason, had difficulty being heard. And now I am a parent with a child that I speak out for, and I hope I am empowering him to speak for himself. I am particularly gratified when I watch mothers change from being initially frightened, to advocate for their child, to becoming a positive and strong voice for their child. First they must learn their child's rights and then they have to learn how to speak out for those rights and ensure they are being met. This is such a challenging metamorphosis that we go through. We have to learn if we are going to help our child, we need to speak with our own voice, to passionately advocate the needs of our child. This is a gift I could not have acquired any other way. I think it is a positive aspect of having a child with autism; it transforms many mothers from timidity to empowerment... (Laura, mother of Sean)

Mothers in the research study expressed sympathy with those mothers who have not yet discovered their voice as an advocate for their children, and how such a voice can have positive effects for the mother and the child. As one mother describes it:

I am able to advocate for my son. However, for many parents it may go against their culture to disagree with a teacher or principal or insist on something their child requires from the school or an agency. Advocacy is in part, what I try and help parents learn. I try to help them learn to speak for their child for no one knows him/her better than they do. Parents need to know what to say if their child is being treated in an unacceptable manner and they need to know what resources and funding is available to them and how to apply for those services. (Laura, mother of Sean)

As discussed by one mother, mothers need not feel guilt about their advocacy efforts, but should feel good about how their advocacy may help others, as everyone will have a different style of advocacy that supports the needs of their children:

So it's [advocating] an ongoing process all the time, and that can be, I mean, one thing that happens is you, ... not just the public, but kind of the professionals almost kind of put it back on you that you have to be an advocate for your kid, well you're tired and your busy, you know, and you have this kid, so I don't think people should feel like obligated. I guess your obligated in the same sense anybody is to do the best you can for your society and whatever way you can, and you know, if your way is advocating for your kid that's terrific, because you will be advocating for every other kid out there too, but if your way is doing other things, that's fine to, you know. You don't need to feel any extra guilt for anything your can or can't do. (Lisa, mother of Matthew)

"I always encourage my kids": The reciprocal nature of the mother-child relationship is demonstrated through the mothers giving to their children what they feel their children have given to them, growth of the self and a sense of empowerment (e.g., advocacy). For many of the mothers it was important to support, have expectations, and encourage growth within their children, which they believed would only lead to positives in the lives of their children. The learning and growth they wanted for their children were either specific to the nature ASD (e.g., social skills), or to their children's demonstrated strengths and qualities.

As one mother explicitly describes the encouragement she instills in her son, and how he has taken that encouragement and given back to others:

...let the child know that they can be anything they want to be, and that they are so smart, and they are smarter than those kids that bully[them]. I always tell my son "You are smarter than those other kids, and you're going to become something one day", and I hope those other kids do, but you know what that's their choice what they do, people make choices whether they are good or bad. So I try to teach them what their choices are in their lives..., and it's hard to explain things to some autistic child[ren], because ... you can't explain it the way you can to somebody else because they don't intake it as well, but you have to at least try to explain. It was funny because hearing him speak to other adults or kids and encouraging them, I was like "Where did you learn that?", but something that you give to them, they can give to other people too. (Sheila, mother of Jonathan)

Other mothers discuss the encouragement they give to their children in order to support their self-growth:

And I am very positive with Crystal, she's asked me, she knows she has autism, and I tell her, because she's asked me, she is smart enough, sometimes it is hard because she is smart enough to be aware, and I just tell her "you know you have few unique things, and you know it's not the end of the world, everybody has a few unique things and we just have to work on that". So in that way it is very positive. (Amy, mother of Crystal)

I needed to learn that Sean has an innate desire to overcome and be included. Sean loves drama and theatre and he's been part of an improvisational theatre group for 4 years. On the first day of school in Grade 9, the drama teacher said to Sean "You don't belong in this class" to which my son replied "I have the same right to be here as anyone else." This came from a child who for years could not speak spontaneously and expressed his emotions through characters in videos, but because of his strong desire to be included, he found his voice! (Laura, mother of Sean)

...I see you know a bright future, we are looking for a little house now, we are fixing up the condo, because we want a little garden you know, and I'd like a little rec room for her, even a finished basement with an apartment, because I've always said to her, I even said to her "you know Crystal you always have a home here," but if she wants to try different things I certainly would encourage that, because I see how happy she is you know, she needs that independence from me you know. (Amy, mother of Crystal)

... it was trying to just encourage him that it wasn't ok for them to [bully him]...and you have to encourage the kids to speak up, because they don't speak up, and they'll hold it inside, and then you get a depressed kid and somebody that wants to hurt themselves. So I went through all that stuff, it has been a road..., but I never gave up, and that's a key thing is never giving up on your child. I always encourage my kids, Jonathan mostly, if you fall down you pick yourself up and you start all over again, tomorrow is a new day, today is a new day, forget about yesterday if it was a bad day...They need a lot of encouragement ... everyday you have to tell those kids "I am proud of you, you are doing a great job, look your smart." (Sheila, mother of Jonathan)

Laura discusses the importance of incorporating encouragement and support of the child's potential into parenting (mothering) practices :

When I am talking to parents, I tell them to have high expectations for their child and to not underestimate their potential. I encourage them to teach their child the things they are going to need in life, for example how to prepare a meal, how to use an alarm clock to wake themselves up in the morning, how to tell time, understand money, those kinds of things. For children who may have a different level of ability, they need to know how to get dressed, use the toilet, etc. Regardless of their level of functioning, they need to learn

what we all need to learn to succeed in the real world, things like courtesy, turn taking and having a giving heart. These qualities have to be taught no matter what the child's abilities. Sometimes, parents see everything their child does through the lens of autism and then we start making excuses for not teaching these things. (Laura, mother of Sean)

In addition, some mothers discussed the inspiration (and hope) they got from well known individuals with ASD, a further way of encouraging their children:

... I read about Mozart, and Steven Spielberg, and Bill Gates, and all these famous people, and I have the book, and what I did was I started reading and researching about their characteristics. I tried to encourage Jonathan and say "look at all these famous people, just because they don't have any eye contact with people and they are not as "Hi how are you?", and really high energetic, look how smart, they've great minds". That is one thing I focused on was [that] he wasn't alone in this world with that disability, that there were other people in the world that were successful and they made it, I mean their great people. (Sheila, mother of Jonathan)

... look at Temple Grandin. She has always loved animals and spent a lot of time around them. Her unique viewpoint has enabled her to be an engineer who has designed more than 2/3 of the cattle handling facilities in the world. (Laura, mother of Sean)

Some of the mothers specifically discussed the importance of family in regard to the bonding and connection that results, and therefore encouraged that type of bonding to take place in the lives of their children:

Keep encouraging him, there's times when I am frustrated, and I think that's quite normal, I wouldn't say that I was a perfect parent either by all means, but just, I think encouraging the child, and what I try to do was keep even family members close by, the kids, I would have a house full of kids all the time, even though I am like stressed out with all the kids, I just kept wanting all the kids in there, I just thought it was great for him to be social with the kids. (Sheila, mother of Jonathan)

At the time I always had to hire someone, because family by this point were kind of freaked out about the whole thing, and weren't that comfortable, although you know I kind of keep that bond going because it is important for Crystal, she doesn't have brothers or sisters, so having cousins, and she loves them, she really does. (Amy, mother of Crystal)

2. "You will grow with them and your love will grow"

All the mothers in the research study talked about the love which exists in their mother-child relationship. The following four sub-themes capture this: a) "everyday more love", b) "lots of joys", c) a positive outlook, d) "everybody likes to feel their children are valued in the world."

Everyday more love. The mothers in the research study were very candid in expressing the love they have for their children as being a positive quality of their mother-child relationship, and describe a love for their child that continues to evolve: For Amy the love for her child was instant, however, learning new things about her daughter's individuality and sense of self allows her to continually fall in love with every new discovery:

And I just loved this baby before she was even born, like most mothers..., you know I just loved her to bits you know, she was the light of my life...I really believe she's the best thing that has ever happened to me. ...I always said I fell in love with her, and I continue to fall in love with her, it wasn't like instant like, there was protection there instantly and instinct, but everyday more love. (Amy, mother of Crystal)

Other mothers discuss the positive emotions they feel toward their children:

We were bonded incredibly, he was my first child, I had him when I was 38 and we were inseparable. I really felt he was my miracle child, he was just adorable, and he was very loving and affectionate. (Laura, mother of Sean)

...there is love, I love him very [much]. You know, with all and all I am proud of him that he is doing well, that he has been able to achieve what he's achieved (Irene, mother of Joseph)

You can lose focus on the child because it is very frustrating at times, but you just give them so much love and you get it back, you get all that love back, like other than having a raging teenager, they are great people. (Sheila, mother of Jonathan)

Laura, mother of Sean, specifically discusses the positive emotions she feels in connection to the qualities she sees in her son (e.g., an educator, bravery)

...just learning how to love your child unconditionally, sounds like such a cliché, but it is so essential....And Sean ended up being this incredible teacher to me, because first of all he taught me that within every individual there is an intrinsic desire to be your best. Although I know I helped my son, more importantly he helped himself. I don't think

parents of young children with autism know this. They feel so responsible for the outcome of their child. The other thing Sean taught me was how important friendships are to him. We make assumptions about people with autism that they don't need or desire relationships the same way as other people do, but this [is] not what Sean taught me. He has a strong desire to have friends, and to me he is one of the bravest people I have ever met. I have watched him try to make friends and he doesn't know how, and therefore he experiences rejection every day. If it was me, and I experienced that type of rejection every day, I would have given up. Sean is in high school now, and he stands around trying to join in, and while there [are] a lot of people who are nice to him, he still experiences a lot of rejection. How many people could try like that day after day? Sometimes in the morning, waiting for the school bus, he stands at the door and he'll ask me "today will be better, won't it mom?" I just can't help but celebrate a person who just keeps trying, to me that's just phenomenal and I admire him so very much. (Laura, mother of Sean)

There is no doubt that mothers of children with ASD experience challenges in raising their children, however, this does not diminish the positive emotions they have and continue to develop for their children. In the following descriptions mothers acknowledge the existence of stress and frustration in being a mother to a child with ASD. Within those descriptions the mothers demonstrate that they maintain their positive emotions they have about their children:

I think the stress is really ever present. So what I try to do now is see the humour more, and laugh more with my son. He says some really funny things, and I just try to enjoy him more. (Laura, mother of Sean)

And, you know my patience wore thin sometimes, but I've always been positive, and very positive with her...we are very connected, because there is just her and I, we're very bonded. (Amy, mother of Crystal)

He's has always been a positive kid, you know I've always been very lucky that way, he's a happy guy, I mean he has his bad times, there are times you have to talk him down when he's frustrated and he can't manage things, but umm, he's a pretty happy guy you know. (Lisa, mother of Matthew)

So she's the joy of my life, she just is...you know, I love seeing her, I love spending time with her, but I love breaks as well. I like going to work now because I know she..., I only enjoy working if I know she is happy, I think that is probably any mother. So I got blessed with this child and that's how I look at, and I figure that's the best way because that gives her positive feelings about her self too. (Amy, mother of Crystal)

...you know, having a kid with autism is like ending up in Mars instead, like somewhere you could of never expected, or planned, or, and you know... it does not in anyway diminish, in anyway the love I have for Matthew or the joy I have in Matthew to hate the autism, you now, □ and you know... it does not in anyway diminish, in anyway the love I have fo

As one mother discusses, love resides in all children and it is important for parents (mothers) to recognize this, and engage with their children in ways that will allow that child to demonstrate their love. Through her description Irene captures the essence of building a mother-child relationship, that despite the struggles any effort will be rewarded:

...there is warmth in all children, you just have to pull it out of them, you have to get the stove working in them, you know I think children are not born to be evil, they are kind, they are loving, you just have to know how to pull it out of them, and some it takes less time and others you really have to work hard at it. And sometimes you know, it is not something you reap the rewards immediately, its sometimes takes time, like I said to you at 11 I thought "oh my god", 12, 13, it was horrible, I used to cry myself to sleep it was terrible, "is he ever going to grow up?, ... is the first thing in the morning not going to be a fight ...?", and now I have mornings with less fights. There is hope, but the hope doesn't come immediately it takes a lot of hard work, persistence, there is a lot of tears you shed...it just takes time. (Irene, mother of Joseph)

In response to a question asked by the researcher, one mother describes the closeness she experiences in her relationship with her daughter:

Researcher: How would you say, if any, if there is any difference between the attachment you have with your child and a mother who doesn't have a child with a disability?

Amy: Umm, I think I might be more attached, I don't know if it's necessarily..., I'm a little more protective. A little more part of her life in a lot of ways, I mean it is not like I am driving her to soccer, or dropping her off, or she has friends which she stays over night, that would be great but that's not the life we have because of the disability, so I don't know, we are just like two, I think we are closer, I think we are, I really do. I mean it's hard for me to know how another mother feels, but I think any mother feels that, but I have to really think of her more, like because everything I do, or everything has to be planned... □ . don't know.has to be plannedr mother feels, but I think any mother feels that, but I have to really thwith her in mind, probably even more so than another parent who is thinking "ok they'll get married, move out, and get a job", mine is more like I did a special will, I looked into that, you know there is [a] trustee, I know she can't keep

[more]than a certain amount, so I am doing the best I can to make sure that she has, everything I do is really for her, if we buy a house that is so she can have that, or whatever she does you know that's her security ,both of ours, but for her. (Amy, mother of Crystal)

Lots of joys. Some of the mothers specifically highlighted the significance of moments they share with their children. The special moments the mothers discussed were based on moments when their children demonstrated affection towards them, having quality time with their children, and engaging in activities that are enjoyable to their children. Amy, a mother of a sixteen year old, discusses the affection she receives from when her daughter was a child to currently, and the positive impact such moments have:

When she gives me a hug, or touches my hand, or holds my hand, [or] comes to me, it's so worth it. ...maybe other people get more of that, but it doesn't mean, we may not get as much of that but when we get it, oh boy it is just great!!, I think its [means] even more. (Amy, mother of Crystal)

Other mothers also share accounts of joy they have in their mother-child relationship:

He has a very sweet nature Matthew; he's a very sweet guy. He kind of likes to tease and joke, and play on his level, you know. ... Certainly when he was younger there were lots of hide and seek games, and [he] loved to go to the playground, loved to go to [amusement park], loved to you know, loves to go places to do stuff. There were lots of joys that way. (Lisa, mother of Matthew)

So we set up goals every year, you know to work on, like if it's safety on the bike, oh they thought she would never ride a bike, this child, I had to get a bike to keep up with her! So don't let anybody tell you, never say never, be positive, because your child is going to feel that, and you know, and naturally most people love their child, that's instinct. (Amy, mother of Crystal)

One mother, Sheila, captures the essence of her mother-child relationship by describing how the joys are experienced into time spent with Jonathan, the personality of her son, and the affection she receives from him:

Researcher: What would you say have been some of the joys in your relationship?

Sheila: The joys would be just seeing him appreciate things, just doing stuff with him, taking him places and stuff, and just spending one on one time with him.

Researcher: So what aspects of your relationship with your son do you find most meaningful and enjoy?

Sheila: What I enjoy is Jonathan is very kind, and he's very warm and he [likes to hug], like he always wants that attention, like "do you love me or I love you"... he's very, very affectionate, and I am like that's just the way he is ... [He is] always trying to say nice things and stuff...

Researcher: makes you feel warm and fuzzy inside!

Sheila: and makes you feel like there is a kid there that, there is a big heart inside there.

Researcher: Do you think that is sometimes overlooked for children with disabilities?

Sheila: A lot of people look at it like he is being a mommas boy, and that I am overprotecting him, and I am to mushy with him, but people can say what they want, but he needs it, and you know what, I don't think a parent can stop wanting to have hugs! (Sheila, mother of Jonathan)

Everybody likes to feel their children are valued in the world. The mothers in the research study acknowledged their children's potential, and see the value in their children, irrespective of the diagnostic characteristics associated with ASD. Which demonstrates the importance of focussing on who the child is as a person:

Because much of the language about children with autism described in books and on the internet, tell us as parents how we need to help our children to change and be something more. But there is a difference between helping your child be all they can be, and helping the child be what you think they need to be... (Laura, mother of Sean)

I have always had the attitude that if nothing else Matthew is here to educate other people. All the way through, he's done that to the other kids he was with, he's done that to the adults, to the teachers at school, I don't know any teacher we ever got that who knew anything about autism before they got him, and knew a lot when they left. Well he was an educator for everybody. I think as I said especially when Matthew was first diagnosed we didn't know anybody with autism, and nobody at the day care had ever seen anybody with autism, you know, and the fact that we now had some resource people coming into the day care and saying these are things you can do with the kids, was a great education for the rest of the staff, the fact that he was playing with the other the kids was a great education for the other kids, you know, like I said, now you got all these kids out

there that think "Oh yeah, I remember the kid like that, yeah he's nothing to be afraid of." (Lisa, mother of Matthew)

Sheila: You know what I've often said I would rather two kids with autism than two kids without it.

Researcher: really?

Sheila: Yeah, I'd said I rather have two Jonathan's ..., because I think their smart enough.., if you give them the proper guides their goals are going to reach higher levels, they will I know my son he wants to strive for 100%, he's going to do it, [he will say] "I'm going to get a 90 or I'm going to get a 95 today", I'm like "Good for you." (Sheila, mother of Jonathan)

Two mothers discuss how other people have recognized the value in their children, and how they were proud that others saw what they already knew about their children's potential:

....but you know this kid will go on most likely,...the kid [Joseph] is very ,very bright, and we just got his report card and he finished with a 75 average, and every single comment " it is been a sheer pleasure to have him in the class, he is a bright [kid], he will go far in this world". Every single teacher. ...the teacher called my husband at work...and she says "Mr. Julian, had to call you to tell you that I am just so impressed with Joseph and his composure, and how he is learning, and how bright he is, and why didn't anybody ever notice this?" (Irene, mother of Joseph)

When he [Jonathan] was in grade 10 he walked across the stage and there were three awards he was getting, and of course mothers I'm like "oh my god!", and all the kids, because he was different, were like "Jonathan!", they were shocked, and then after that they were going to him and asking him questions, they respected him more. (Sheila, mother of Jonathan)

One mother specifically discusses the opportunity to talk about her child's value within the context of this research study:

I really appreciate studies like this, I really appreciate the opportunity to talk about Matthew, and I hope it helps somebody else, you know. I appreciate that, and to educate other people, it umm, you know everybody likes to feel their own value in the world and their children are valued in the world, you know, and as I said, "you know Matthew may never build a bridge or do a lot things other people's kids do, but he has educated a lot of people and hopefully he has made it easier for a lot of people coming up behind him, and I appreciate that opportunity." (Lisa, mother of Matthew)

A positive outlook. Mothers discussed explicitly and implicitly the importance of maintaining a positive outlook, and the role it plays in their mother-child relationship:

I never looked, I don't look at it as a negative [ASD] because I don't want her to look at it as a negative, and I don't want other people to look at it as a negative. (Amy, mother of Crystal)

And I do believe there is a reason you got that child because someone, if you believe, I believe in God not everybody will, but I do believe that someone believes, that child was coming no matter what and it got picked to go with you, so you were the one, so there is something you have in you that's the right thing for that child. That's how I feel. (Amy, mother of Crystal)

So I am positive, and believe me there were times when even my family you know would say "what are you going to do, what's going to happen when she's older," and Dr. Smith and I were talking and she said "well why worry about that, take one day at a time", and she is absolutely right. Or my sister would say "Well what do you think happened? What is it? Is it the father's side?", and I said "you know what I really don't care, this is the child I have, I have a lot faith, I believe I got her because I can take care of her and love her, and so.... what does it matter how this [ASD] happened, this is my child." (Amy, mother of Crystal)

I think you just like any child you find joy in the gains they make, even if they are less gains than your other children, you know, umm there' times when they can really surprise and impress you, his umm, about 3 months ago his stepfather showed him a little video on clip on You tube [online video posting website] and the next day he started looking up all kinds of things in You Tube, I didn't know he could use You Tube, now he does all kinds of stuff on it. So there's always little surprises and things that'll happen along the way, which is true again of any child. (Lisa, mother of Matthew)

And realize that it's not going to be a death sentence, you are going to have lots of joy everything can be worked out someway, like I would like to take Crystal down south, and I mean how am I going to do that, well you know what I could phone the airport ahead of time, we could board early, we could, you know there is even a discount for me to go with her, so you start to find out that you know people are pretty accommodating, the world is trying to be. (Amy, mother of Crystal)

When asked about getting to know her child for who they are irrespective of the diagnostic characteristics, one mother had the following to say:

So it wasn't hard for me, because even seeing those, those are just like outline, but there is a whole person there you know with a personality, and plus I don't really believe, you can't just be negative and say "ok that's it, that's what they are, and you know, I might as

well forget about trying anything else, and just stick from here", no, no, no, no, you have to be positive. I am a positive person. (Amy, mother of Crystal)

When asked what advice she would give a mother who has just found out about their child's diagnosis of ASD, in regard to the mother child relationship, one mother said the following:

I'd tell them to remember who their child was before they ever heard the word autism, and to celebrate who their child was before they ever got the diagnosis. (Laura, mother of Sean)

Other mothers also provide advice to mothers of children newly diagnosed with ASD:

To realize there is support here for you, this is not the end of the world, it's just a different world, and it's not what you expected but, .. I think empowerment would be really good, and not to blame and to help them not blame themselves, because of course you do. (Amy, mother of Crystal)

Irene: Stay as calm as you can, don't cry in front of the child, try to seek out help, don't let people tell you there is nothing available, be persistent. If you feel it you know it, go after it, work with your child, encourage family members to understand and be more of a resource to you,but don't give up, go and find out, and even in your darkest days where you think "I am going to walk away, I am going to leave my husband, I can't do this anymore, I can't it is killing me", God will give you the strength to carry on, take that deep breath, go out for that walk, go to the gym and punch the ball, go on the treadmill, go on the elliptical, do you what you have to do, but have the sanity to get out of the house when it get's to much the pressure cooker, and try to have someone to give you respite care.

Researcher: Is that really important?

Irene: respite care is super important, we didn't have that, and had we known it does exist we could of gotten it, but you know you have to ask for it, you have to find about it, and people don't know about it...And love your child for who he/she is, it will get better,...you got to laugh about it! (Irene, Mother of Joseph)

3. *"Find support where you can from people who will understand"*

The mother's discussed the importance of receiving support from various sources throughout the years. They felt the support has a positive impact on the relationship they have with their children, and was an essential part of their lives, and the lives of their children. They

felt the nature of the support they received gave them the skills and an outlook needed in facilitating their mother-child relationship. The support was a source of, and facilitated confidence in being a mother of a child with ASD. Overall the range of supports the nature of the mother-child relationship, as one mother said "...whoever you can get who can build in that kind of support for you and your child, that's going to support you and your child's relationship." The diversity of support ranged from words of encouragement, mothers feeling their children are accepted and understood, taking care of the self, and parenting strategies. Three sub-themes emerged out of the data analysis: a) formal support system, b) find the balance; I know if I feel good that's going to impart to my child"

Formal support systems. Some mothers specifically expressed the value in receiving support; they felt it was beneficial to the developing relationship with their child. The nature of the support gave the mothers the skills to address the needs of their children. Mothers also felt the support was encouraging to their confidence in being a mother to a child with an exceptionality, and also provided them with a sense of understanding and acceptance:

...there needs to be support for the parent, one of the things I liked about the [support program] and they continue it now with Speech and Language, is the following your child's lead work they do, and I went to the session where they video taped me interacting with Matthew, and then you watch the video tape after and you talk about how you can interact and stuff, you know stuff like that is very supportive, you know somebody is watching you and saying "oh look that's great what you did there, and here you could do this as well." I think that is very supportive, and so I think when you are looking for interventions for your kid anyone that involves you is going to support you. (Lisa, mother of Matthew)

One mother expresses the importance of support for her child as well and his sense of empowerment:

....they need more support, Jonathan had great support, it built his self esteem to the top, because he was allowed to go out of his class and into the core resource teacher if there was noise in the room ...he doesn't like noise and it's too distracting to him. He felt like

he was empowered to go into another class and sit, and "I can do my homework alone", and he was great, but it was in a room by himself and he was quiet. That was a good encouragement for him and that helped him, otherwise he would have sat there got frustrated, not done the work and got a bad mark on it, but by helping him and giving him the proper services that he could have, [it] helped him get through high school with honors! (Sheila, mother of Jonathan)

I go to a support group..., it's [a] parenting support group, I have been going for a year and a half. That support group has really helped me a lot, the tools I have learned, I have used on Jonathan, how to speak, not engaged, not ask so many questions, that's helped to go to parenting groups...and I guess for me is to just continue to get as much support as I can for myself, to be a better parent. (Sheila, mother of Jonathan)

As one mother expresses, parents and their children with ASD can feel alone. However, by receiving support, mothers and their children are sent the message they are not alone:

I know there are a lot of support systems out there, and it's just a matter of researching and making some phone calls. I mean it's there for the parents, and the supports there for the kids and they can all sort of not feel alone. I think that's beneficial for the kids, because a lot of kids feel like they are alone, and they are different, and they need to not feel that way, you don't know what is wrong with your kid until you do find out, and it's like you have a different aspect on parenting when their like that, because you don't want to make them feel like they are different, they are special. (Sheila, mother of Jonathan)

The need for support was also recognized when engaging in activities with the child. Lisa stressed the importance of being in public with your child, and ensuring there are supports available in order for that to happen:

And even in the public, I think that it is important that he [Matthew] is out there. And yeah people stare, and yeah it can be uncomfortable, and you get the odd person who reacts badly, but you get some very friendly people too, and you, it's very dangerous to feel alone, to feel like you can't go anywhere, so go out and go anywhere, go to the Zoo, go to Centre Island, you know. Get used to being out there and how it's going to work for you, and what you need to get out there? What kind of support you need to have with you? You know, it's something you have to do, because you could very easily end up with you and him in a room, you know seriously. (Lisa, mother of Matthew)

One mother describes her mother-child relationship as a journey through the support she received from a man diagnosed on the autism spectrum. She describes the time when her child was initially diagnosed she was filled with fear, "... this child I was absolutely fearful for, and I

moved from being a parent to somebody I who I felt had to fix him". Through the support she received she was able to get to a place where she could once again celebrate her child for who he was and who he is today.

I went to the [Community Support Centre] to hear a panel of adults share their life experiences of living with an autism spectrum disorder. I remember that there was one man in particular; he was so articulate and insightful. I went up to him afterwards, tears rolling down my face, to ask him if there was any way I could speak with him again. He gave me his phone number and later he visited our home and met Sean. He offered to share with me for as long as I needed to, and it ended up that we spoke every Wednesday night for about a year. Those conversations were probably one of the greatest gifts God ever gave me. Because of this man's insights, I could see that some of the things Sean was doing had nothing to do with autism. I learned that autistic kids grow up to be autistic adults; that they have strengths as adults, and though they struggle with loneliness and the social difficulties remain, they still have many abilities and that was hugely helpful. After a year of talking on the phone, his name was Greg, (pseudonym) we started a group so we could share our insights with others. We formed a group with adults on the autism spectrum and people from various agencies, an interchange of adults and professional speaking to one another. With the help of [Community Agency] we created a booklet and a video to share these first hand experiences. I also co-wrote a booklet to give to parents, because I didn't want any parent to go through what I had gone through, being given a diagnosis of autism and being sent on their way totally uninformed and ill prepared. The booklet contained a description of autism, frequently asked questions and first numbers to call to get support and funding. So that's my story of how Sean went from being this absolute treasure to me, to being the child I was absolutely terrified for, to coming back to being the child I celebrated again. This was the journey of an adult with autism helping me reclaim that my son was okay the way he was. (Laura, mother of Sean)

Overall, the support has been....

Many parents who have children, who are moderately affected, not on the severe end of the spectrum, need to learn to be able to pace ourselves somehow. There have been a lot of good people who have supported Sean and me over the years in unexpected ways. I look at them as angels, in a way. They came, they gave and they didn't expect very much in return. They helped us and now they've gone on their way, but we benefited so much from them. (Laura, mother of Sean)

I think just you know get as a much information, do take care of yourself, and never give up, just love them cause it will come back, it will come back to you. (Amy, mother of Crystal)

For us who are single moms, we need to ask other family members or good friends or find respite workers to help us, because going it alone could result in burn out, or

resentment of your child, or yourself, or your life. Because the demands can be never ending and the field of autism is still, in many ways, uncharted territory... (Laura, mother of Sean)

I think that feeling of that you have support would be extremely, for mother mothers, because I was searching for other mothers to talk to when I was first with Crystal, and it was such a wonderful thing when I did connect with someone on the phone who totally understood me, who I could even go visit and not worry if Crystal did weird things, people wouldn't look at me like you know "what's the matter with her child?, why is she doing this or that?", yeah that's really helpful, so support groups of other mothers. (Amy, mother of Crystal)

...find support where you can from people who will understand. Build that support early age and keep it going, I know one thing that has really helped is I have a group of friends, some of them I've known, actually one of them since kindergarten, but they all had kids the same age as Matthew, and every summer we go away camping with them, you know, and everybody goes, and because they all know Matthew and they've all known him since he was little, it's you know, it's, you don't feel strange. That's one of the hardest thing is that you feel so strange around normal people and normal kids. And so the more people who know your kid and are used to your kid, and are going to, you know, those family supports, you know the larger family groups, friends, parent relief workers, whoever you can get who can build in that kind of support for you and the your child, that's going to support you and your child's relationship, you know. (Lisa, mother of Matthew)

in the darkest point, the darkest period I think I had two friends who were very, very supportive, both who interestingly have children with special needs, and who could understand what it could be like, and supportive that way. (Irene, mother of Joseph)

When Sean was younger, every time we would go to the developmental paediatrician, I would give an account of all that I had been doing to help Sean. The doctor would always respond "you are fantastic, Laura, you are like a super mom." This is because the onus falls on the parents. They feel that much of the progress their child is going to make is often due to all the hard work they put in. This overwhelming responsibility made me feel like I was dying on the inside, though my words and actions spoke of my competence. I was frightened nearly all the time, constantly questioning whether I was doing enough to help my child. Eventually I got thyroid disease, and I think (pointing to throat) it was really a suppressed scream for help, crying out that I felt overwhelmed and afraid. Getting ill has taught me that there is no merit in acting strong all the time, and it is really important to find safe people you can be vulnerable with. (Laura, mother of Sean)

Find the balance; "I know if I feel good that's going to impart to my child." Mothers in

the research study felt that it was important to take care of themselves in order to create a sense

of balance, and be able to be an effective mother to their child and family. Some mothers also

discussed the importance of recognizing and validating their feelings when it came to needing a break:

I can't overstate the need for a mother to find the balance in her whole life, and for me it is encapsulated in the serenity prayer - to be able to differentiate what I can change, what I can't change and the wisdom to know the difference. I needed to learn what I could do in this one day without over extending myself, taking into account my health, my marriage and my other children. (Laura, mother of Sean)

Because the real danger is to feel that you and your kid are alone in this, that's a real dangerous place to be, you know. And so that is really important, use the parent respite, don't feel like you are the only one that can take care of your kid, because that is not good for you or your kid. (Lisa, mother of Matthew)

With me, like you know especially in the last few years, things have gotten easier, I have treated myself to a manicure, pedicure a little more often, I don't think I am high maintenance or anything, but I know if I feel good that's going to impart to her, you know, not like "oh I had to give up so much for you," I mean who wants that, I mean along as she has everything she needs. (Amy, mother of Crystal)

...so make sure you use the respite you can find, to get out with your partner, and make sure you work on that relationship too because you are going to need that you know. (Lisa, mother of Matthew)

4. *All I want is the best for my child's future.* The mothers recognized the challenges their children experienced due to ASD primarily being a social deficit, however, mothers encouraged and supported social interaction for their children because they know the benefits it will have for them. Mothers also discussed their children's future (e.g., will they have people in their lives that care about and support them?) as a constant thought on their minds. In addition, some mothers specifically recognize the lack of services as their children become adults, as one mother says, "you just think everything is going fine, and then you hit the school system and its like hitting a brick wall, and then you get through elementary school and you hit High School and its like boom, and then you get through it all and hit adulthood and all of a sudden there is no services and your going boom again you know." (Lisa, mother of Matthew)

There is a part of me that is still on edge, even with all I have learned about autism. I am still responsible to ensure he gets the support he needs throughout his school years. Sean is now in high school and once again my experience has been that many of his teachers have very limited experience teaching a teen with autism. There is this concept that some teachers have that if they have previously taught a student with autism they can apply what they did with that individual to the next student they have with autism. But I like the saying that "if you've taught one person with autism, you have taught one person with autism." Each person is unique and the profile they present is individual to them....so when a teacher generalizes the strategies they employed for one individual with autism, it may or may not work for another. Yes, there are a cluster of difficulties that individuals with autism share - problems with social interaction, a need for sameness, sensory sensitivities, but the manner in which these difficulties are manifested is completely unique and there is great variation in abilities. I believe for most parents, that dealing with the education system is the second biggest challenge after receiving the diagnosis. (Laura, mother of Sean)

.for mothers in particular, there is this burden of responsibility where you continually ask yourself, "Am I doing enough?" This question is always in the back of your mind. (Laura, mother of Sean)

One mother discusses the current state of service delivery that families are faced with, and her role in ensuring that she empowers families to be confident in their role as parents:

Laura: When Sean was younger, autism wasn't very well known. Today there is a lot of media regarding autism, but the problem remains, lack of resources. Thirteen years ago, there were few resources because autism wasn't well known. Today there are more resources but the wait lists are very long. So really, I don't think that much has changed. Parents feel constrained by what therapies they can afford. It is a two tiered system...

Researcher: I've heard that before

Laura: It absolutely is. If a parent can afford private therapy, then their child doesn't have to sit on a waiting list. In regard to IBI (Intensive Behavioral Intervention) the children on the wait list must meet a strict criteria to receive government funded IBI. Those who do not meet the criteria and can afford to get private IBI don't have to wait for therapy to begin. I don't know how much has really changed over the years. One of my goals is to empower parents, no matter what resources they have, to trust their own intuition about how to help their particular child and to learn as much they can about autism. I encourage them not to lose sight of who their child was before they ever heard the word autism. (Laura, mother of Sean)

Your child is not invited: Mothers see the importance in social interaction for their children and also understand the impact limited opportunities for social interaction have on their children:

When you have a child and he's born, and you have this little precious little gift, and you watch that boy, the smiles, and then you watch him just disengage from the groups, and he's in his own little world, it's hard to see that, because all these kids are all excited, and their singing and dancing, and he's like "I don't want any part of that" so that part was really hard growing up... (Sheila, mother of Jonathan)

When you are picking your child up after school and you see the other kids going off to somebody else's house to play, and your child is seldom invited, that's heart breaking. When you see the other kids talking about going to a birthday party and your child is not invited that's heart breaking. There were some kind parents, back in kindergarten, who invited the whole classroom to their child's birthday party, but most of the parties our kids were not invited. It is very hard to organize play dates. You can invite other children over to your house for a play date, but often times our children run away or seem unsure what to do when other children come to play. Autism is primarily a social disability, and when you see other kids getting together, and your child is not included, it hurts both you and your child. My 14 year old daughter is always with her friends and my son is at home with me. At 17, he would like to be out with people his own age; he doesn't want to be hanging out with his mother. (Laura, mother of Sean)

I tell Jonathan, "I really like you to be social and this and that, and I feel really badly that you are sitting in the house everyday..." (Sheila, mother of Jonathan)

"You are now telling me that I have to live forever": Mothers did express their concern for their children's futures because there was a sense of the unknown. The mothers realize the role they have in their children's lives, and that sense of concern is a result of imagining what their children's lives would be like without them. Captured in this sub-theme is an essence of feeling like as a mother you have to "live for forever" to make sure your child is going to be taken care of appropriately.

There is always this sort of struggle within me where I worry and then I try to let go. I help as much as I can and then I try to let go. (Laura, mother of Sean).

Well there's, what was the name of that book ..., somebody wrote a novel just recently, it was a British one about having a child with autism, looking for Daniel, I can't remember,

but I remember a line in the book, because when the Dr. told the mother the diagnosis, she said "you are now telling me that I have to live forever." And that one really struck home, because that's always with you that worry, that what's going to happen if you are not there for your kid, you know, and it, that one never, I mean it's always kinda in the back of your head, so even when other things are going well, that's still there at the back of your head, you know, that you have to work on that. (Lisa, mother of Matthew)

Because much of the language regarding autism, in the media, books and on the internet tells parents how early intervention affects future prognosis, I have learned that there is a difference between helping your child be all they can be, and helping your child be what you think they need to be. This difference is driven by fear. Almost every parent I believe has a fear that their child is going to be bullied, and we worry what could happen when we are not around. What happens to my child once I am gone? Who will look out for him? What kind of employment are they going to be able to have? Where will they live? How will they be able to function? And because of the social difficulties, as they grow older, will they have people around them who care or will they be alone? The fears change as time goes on and we wonder if they will have people around them that care about them? Will they have a mate, somebody that they will love and who will love them in return? What does the future look like? (Laura, mother of Sean)

The findings of this research study extend our knowledge of the mother-child relationship amongst mothers of children with a diagnosis of ASD. As described by the mothers, the mother-child relationship is experienced as learning and growth of the self, love for the child, in addition to being positively impacted by supports. The mothers attribute positive growth and learning of the self to their children, and impart that learning and growth of the self back to their children in the way they mother.

Building a bond through learning and growth

The nature of the mother-child relationship has not readily been explored through maternal narratives specifically amongst mothers of children on the autism spectrum. The findings demonstrate these mothers do acknowledge a relationship between themselves and their children, and demonstrate to us what that relationship is about and how it is experienced. Assertiveness, compassion, advocacy, understanding, and how to love are some of the qualities reflected in mothers' growth and learning; qualities they feel their children have brought to their mother-child relationship. The growth and learning the mothers experience brings them full circle, it is as if their children bring into their lives the skills they would need in order to support the child, and positively discover and experience the mother-child relationship.

In contrast to the previously mentioned research studies, a unique finding of this research study was the mothers' discovery of their inner voice as being a positive aspect of their mother-child relationship (e.g., advocate). The ability to find their inner voice and, therefore, become an advocate meant their children's rights would always have a voice within society. Becoming an advocate is as much a transformation for these mothers as it is for their children, because through a mother's advocacy work she is paving the way for her child to be respected and included

within the society they live. Similarly, in a Canadian research study on mother's experiences of raising children with exceptionalities, Panitch (2007) demonstrates how mothers become "accidental activists" as a result of having children with an exceptionality. Panitch (2007) demonstrates how their advocacy work has not only paved the way for their children, but for future families and children with exceptionalities. For example, the mothers in Panitch's (2007) study advocated for "...disability-related public policy, abolishing discriminatory legislation, downsizing large institutions, and revising human rights legislation to include disability as a prohibited ground of discrimination" (p.4).

The notion of growth has been found in other research studies amongst parents of children diagnosed on the autism spectrum (Bayat, 2007; Hare, Pratt, Burton, Bromley, & Emerson, 2004; Montes and Halterman, 2007; Pakenham, Sofronoff, & Samios, 2004). Pakenham and colleagues (2004) found that 73% of parents in their research study experienced a positive personality change as a result of raising a child with Asperger Syndrome. In addition, Hare and colleagues (2004) have found positive advantages amongst mothers caring for a child on the autism spectrum (e.g., mothers "...reported that they had become more patient and tolerant and could appreciate other people's good qualities more...") (p.433). The current research study has extended their findings by demonstrating how positive changes within the mother lend themselves to positive interpretations of and practices in the mother-child relationship.

While narratives have not been used, research studies using self-report measures have attempted to demonstrate the nature of the mother-child relationship; for example, Montes and Halterman (2007) found on self-reported measures of the parent-child relationship "mothers of a child with autism reported having close relationships with the child at the same rate as..." families that did not have a child with autism (p.1043). However, Montes and Halterman (2007)

did not explore specific qualities of the mother-child relationship that lead mothers to report having a sense of closeness to their children. In spite of this, Montes and Halterman's (2007) finding, and the finding from this research study (e.g., growth and learning of the mother) support the social constructivist perspective in regard to individuals as constructors of their lived experiences (Hale, 1995). In their study, relationship closeness was similar to mothers that did not have a child with an exceptionality, their finding combined with the finding from this study demonstrate that a child's exceptionality does not determine the existence or experience of the mother-child relationship. Suggesting all mothers, regardless of whether the child has an exceptionality or not, are able to describe the nature of their mother-child relationship at it is experienced.

Bayat (2007) explored the positive and negative impact of autism on family functioning, his findings demonstrate that positive transformations of the family (e.g., family relationships became more connected and strengthened over time, parents had more compassion, etc.) is an indicator of family resilience (e.g., strength in the face challenges, being able to overcome challenges). His finding support this research study by indicating resilience may be an outcome of self-growth and learning. Such that self growth and learning establish resilience in mothers as they continue to support their children, and see the positives in their mother-child relationship in the face of challenges.

In analyzing the structure of the narratives, learning and growth was demonstrated as a positive experience of the mother-child relationship. Similarly, Fisher and Goodley (2007) analyzed the narratives of mothers caring for infants with exceptionalities, they found that narratives with a focus on "...becoming was identified as one that enables mothers to enjoy their children in the present..."(p.78) Their finding lend support to this research study by suggesting

self-growth and learning may be an influential factor in the development of the mother-child relationship in positive ways, which allows a mother to focus more on who her child is as a person, and to take joy in the relationship she has with her child.

"You know you will grow with them and your love will grow"

The mothers of this research study candidly discuss the love they have for their children, as demonstrated in the following three sub-themes; "everyday more love", "lots of joys", a positive outlook, and "everybody likes to feel their children are valued in the world." They argued that the transformation of their love into these different areas positively benefited the child, and their experience of mothering. In a recent research study that explored expressed emotion (e.g., feelings and attitudes about the child) amongst mothers of children with intellectual disabilities (e.g., autism, down syndrome, cerebral palsy, etc.), through the use of self-report measures, researchers concluded mothers had more negative expressed emotion (e.g., more critical and highly emotionally involved) towards the child with the intellectual disability compared to their other children that did not have an intellectual disability (Beck et al., 2004).

There are crucial differences between this research study, and Beck's and colleague's research study in regard to analysis and the implication of findings. Beck and colleagues (2004) did analyze mother's discussion of love for their children, and their view of the mother-child relationship as part of measuring expressed emotion, however, they did not make a distinction between the love a mother has for her child, her feelings towards the nature of the exceptionality, and emotions associated with parenting satisfaction and beliefs. This is a crucial distinction to be made because negative expressed emotion may have more to do with the nature of the exceptionality, and not necessarily a direct negative view of the child as a person. As a result their findings suggest expressed emotion may be dependent on the child's exceptionality and

demonstrated behaviour (Beck et al., 2004), implying that the mothers in their study have conditional love for their children with intellectual disabilities. Is it fair to think that if a mother is unsatisfied with her ability to do the best for her child, her love changes?

The findings of this research study challenge Beck's and colleague's (2004) research study by demonstrating that mothers do express love for their children with no indication that it is dependent on their child's diagnosis of ASD. In addition, mothers were specifically asked about the process of getting to know the child in light of the diagnostic characteristics, the general consensus was the diagnostic characteristics are an outline of the child in order to support the needs of the child, but that there is more to the child than those characteristics alone.

Mother's acknowledgement of seeing value within their children, and maintenance of a positive outlook about their children also demonstrates the love they have for their children. As the years went on, through seeing the value in their children and having a positive outlook, mothers explained that they focussed more on enjoying their children. Such findings are consistent with Gray's (2006) research findings which suggest that with time, parents of children with ASD, often use emotion focussed coping strategies, as a result focussing more on "...an appreciation of their child's good qualities..." (p.975).

Montes and Halterman (2007) found that when the behaviour of the child's diagnosis of autism was controlled for, self-reported measures of a close relationship were higher for mothers of children with autism, than those that did not have a child on the autism spectrum. Montes's and Halterman's (2007) findings, and the current findings of this research study possibly demonstrate that a more conscious effort is given to developing closeness within the relationship, and as such, is a natural aspect of the mother-child relationship (amongst mothers of children diagnosed with ASD) because of the unique set of challenges these mothers have to deal with.

Giving attention to the value of their children the mothers recognize their children have a place within the society they live in, and can make valuable contributions (e.g., as educators for those who do not understand ASD). In support of this finding, Fisher and Goodley (2007) conclude that narratives that highlight the value of children with exceptionalities tend to "...transcend categorisation of normality and abnormality" (p.78). This is an important point to emphasize, because mothers in this research study valued the qualities they saw within the individuality of their children, which were not demonstrated to be governed by the diagnostic characteristics associated with ASD.

"Find support where you can from people who will understand"

For the mothers in this study support was and continues to be an important aspect of the mother-child relationship. The support focussed on formal support systems, (e.g., parenting strategies, support network of family and friends), and the importance of finding balance within the self. Overall, the mothers feel the dynamic nature of the support they received was beneficial to the relationship they have with their children because it allows them to be better mothers. This research finding is similar with the current literature that demonstrates the importance of support for families of children with exceptionalities (McWilliam, Tocci, & Harbin, 1998). However, unique to this research study are that the findings suggest specific supports (e.g., self care, mother-child parenting strategies) mothers of children diagnosed on the autism spectrum may require in order to support the development of their mother-child relationship in positive ways.

The quality of formal support systems created acceptance and understanding which made mothers of children on the autism spectrum not feel alone. The acceptance and understanding mothers received through a close network of friends, families, and service providers, may be a factor in making mothers more comfortable and confident in their abilities as mothers, because

such support is not dictated by expert knowledge of how to mother their children. In addition, acceptance and understanding may also give mothers comfort in knowing they will not be judged for what they can, or cannot do.

In a recent research study that surveyed parents about the types of supports they need in regard to parenting a child with an intellectual disability, 84.4% (n=160) said they needed someone to talk to (Douma, Dekker, & Koot, 2008). This is an indication that those parents were searching for support in order to receive a sense of understanding of their experiences.

Douma, Dekker, and Koot's (2008) findings lend support to the finding of this research study in which mothers discussed the importance of having a support network that gave them a sense of comfort and understanding, as one mother said "the more support you can get the better, ... There needs to be people who can talk to you about, it's almost like you need someone you can just call at the drop of the hat and just vent at, like an AA sponsor or something". Their research study also found that parents needed supports that are more practical (33%, n=160) (Douma et al., 2006). Although the researchers did not explore what type of practical supports the parents needed, the findings of this study demonstrate that tools and strategies that support the mother-child relationship may be an aspect of practical supports mothers need in the area of the mother-child relationship.

The findings of this research study support the importance of finding a balance within the self as some mothers specifically highlighted this aspect, realizing that without a sense of balance there is the potential to burnout or get sick. Mothers were aware of the positive impact taking care of themselves has on the mother-child relationship. As one mother said "I have treated myself maybe to a manicure, pedicure a little more often, I don't think I am high maintenance or anything, but I know if I feel good that's going to impart to her". In a research

study that assessed the unmet needs of mothers of children with ASD, 89% of families indicated that having a break from caring for the child was an unmet need (Hare, Pratt, Burton, Bromley, & Emerson, 2004). The findings of this research study demonstrate the importance of taking time for the self as a positive factor in mothering a child with ASD.

All I want is the best for my child

There is extensive literature on the emotional impact a child's diagnosis of ASD has on the family, specifically on the lives of mothers (Dale et al., 2006; King et al., 2006; Norton & Drew, 1994). This research study did not specifically focus on the emotional and stress related impact of having a child with ASD, nor did it specifically address the period of finding out about the diagnosis, or accessing intervention services. However, the discussion of these experiences were brought up during the interviews, and were not discouraged or dismissed because they were able to demonstrate a new perspective on the mothers stress related experiences. As discussed within the literature there is a strong emphasis on the stress associated with raising a child with autism (Dale et al., 2006; King et al., 2006; Norton & Drew, 1994). All the mothers did acknowledge the challenges they experienced (e.g., accessing services, the child's behaviour); however, the stress of those challenges did not change the love they have for their children, or their experiences of growth and development in positive ways as mothers.

More importantly, their narratives expressed concern for their children's future and social development. Their children's future as expressed by some mothers is a constant thought in the back of their minds, as there is a sense of the unknown. Rooted in the concern is whether or not their children will have people in their lives that care about them and see their value. The limitations of social skills associated with ASD weighed on the minds of some mothers, as they knew the benefits social interaction can have for their children. The finding suggests stress may

be attributed to the concern for their children's future, but not in a manner which negatively impacts the nature of the mother-child relationship. Rather such concern may mobilize a mother to secure and make arrangements for her child's future.

Challenging ideologies of motherhood; an empowered experience

According to O'Reilly (2006), there are different ways to demonstrate empowered mothering; one of the ways is to mother against dominant ideologies of motherhood. Through their narratives mothers of this research study have been able to challenge ideologies of motherhood, specifically in regard to attachment theory, the medical model, and the ideology of the sacrificial mother. The mothers have demonstrated through their narratives that the experience of the mother-child relationship is an individual experience that is not about conforming to norms of motherhood.

King and colleagues (2006) assert that the literature has portrayed children on the autism spectrum as having a negative impact on the well-being of families by being a factor of stress. Not only are children blamed, but the literature has also implicitly perpetuated the "refrigerator mother" discourse by not acknowledging the emotional attachment mothers feel towards their children, and the different ways mothers express such emotions. The findings of this research study have substantially challenged this implicit, and sometimes explicit, perspective in the literature, as the mothers clearly express the love they have for their children in many ways (e.g., positive outlook, valuing their children's lives). Interestingly, in an article published by a father of a child with autism, he expresses similar emotions about his son as expressed by the mothers of this research study (Anderson, 1991). Anderson shares his appreciation of his son being a teacher to him; in addition to the pride he takes in his son's achievements (Anderson, 1991). As Anderson says in his article, "I do not love his autism, but I love him and he is autistic"

(Anderson, 1991, p.24). Such a quote demonstrates his ability to look beyond his son's diagnosis of autism and all the challenges, to see who his son is a person and to love that person, which is fundamental to the mother-child relationship amongst mothers in this research study.

Within the medical model the diagnostic characteristics associated with ASD tend to erase who the child is as a person (Crow, 1996). The mothers of this research study challenge such a perspective by acknowledging the importance of being aware of the diagnostic characteristics in order to better support development of the child, but getting to know the child is about moving beyond those diagnostic characteristics. In doing so the mothers were able to see their children from a different perspective, a perspective that allowed the mothers to see the value in, and the joy, their children bring to their lives.

Diagnostic characteristics of an exceptionality are implicitly related to being the sacrificial mother, because focussing solely on those characteristics implies that mothers need to be intensive in their mothering practices in order to be able to help the child, in which they simultaneously forget about the self (Blum, 2007; O'Reilly 2006; Rich, 1976). However, the realization amongst these mothers was that taking care of the self can only have positive benefits toward their mothering practices, and the nature of the mother-child relationship. The mothers of this research challenge the ideology of the sacrificial mother by encouraging mothers of children to use respite care, and to not be afraid to ask for help. Essentially if mothers feel good about themselves they will impart this onto their children in ways that are positive and will support the child, rather than if they neglect taking care of themselves.

As discussed, the nature of the mother-child relationship amongst mothers of children with ASD is mainly researched through the strange situation procedure (SSP) (Willemsen-Swinkels et al., 2000; Dissanayake & Crossley, 1996, 1997). The depth and dynamic of the

mother-child relationship is lost when observational methods (e.g., SSP) are used to understand the nature of the mother-child relationship amongst mothers of children on the autism spectrum. The findings of the current study challenge research on autism and the strange situation procedure, because unlike the SSP research which have been done in laboratory settings, the mothers have described their mother-child relationship that has been shaped by experiences occurring in their natural environments.

Lastly, through their narratives these mothers have demonstrated that attachment theory is no longer enough to understand the depth and dynamic nature of the mother-child relationship. Without speaking to these mothers we would have never discovered how self-growth and learning have positive contributions to the closeness experienced in the mother-child relationship amongst these mothers.

Limitations

Although this research study has made an important contribution to the literature on ASD and the mother-child relationship, the study is not without its limitations. Firstly, the sample size was only five mothers of children diagnosed on the autism spectrum, and did not include all mothers of children diagnosed with ASD the Greater Toronto Area (GTA). Therefore, the generalizability of the research findings cannot be extended to all mothers of children diagnosed with ASD within the GTA. This issue is specifically important if the results are to be used to develop intervention and support services for mothers and their children on the autism spectrum. The sample size would have to be larger in order to obtain a more representative sample that would address the type of services families require in raising a child on the autism spectrum.

Secondly, the research study was also limited in regard to diversity; as all the mothers in the research study were Caucasian (although from diverse backgrounds). Therefore the findings cannot be extended to mothers from different racial groups whose mother-child relationship may be influenced by cultural understandings of exceptionalities.

Thirdly, the descriptions of the mother-child relationship only represent the mother's perspectives and not those of their children. Our understanding of the mother-child relationship can be further extended by looking at the perspectives of the mother-child relationship as experienced amongst children with ASD. Our knowledge of the diagnostic characteristic associated with ASD (e.g., limited social skills) (Bowler, 2007), through their descriptions, can be extended in regard to how those characteristics manifest within the mother-child relationship.

Fourthly, one of the main participation requirements was that the child's diagnosis of ASD had occurred in the last five to ten years. As stated earlier, this reasoning was based on research literature which suggests that mothers in the early stages go through various emotions in

understanding their child's diagnosis (Gray, 2002 & 2006; Tway, Connolly, & Novak, 2007), and may not be in a state to discuss their mother-child relationship. However, there was the possibility that research participants willing to talk about their mother-child relationship, in which it has been less than five years since their child's diagnosis of ASD, were excluded based on the diagnostic time frame requirement.

Fifth, only twenty-seven agencies were involved in the recruiting process (by having the research study flyer advertised on their information board) as result not every agency within the Toronto area acted as a recruitment site. Therefore, decreasing the number of potential research participants who met the criteria for participating in the research study.

Sixth, the research study was not a longitudinal research study design; as a result no conclusions can be made about how the mother-child relationship develops over time. The research study captured retrospective and current descriptions of the mother-child relationship during one interview session, which as time passes mothers may have come to understand past experiences differently than at the time of the experience.

Lastly, while the use of the Oral History Method has been criticized for the inability to gather factual information, because there is an over reliance on memories and story constructions of life experiences (Babbie & Benaquisto, 2002b). However, due to the personal nature of the topic the only, as argued in this paper, most effective way to explore potentially positive aspects about mothering a child with ASD and to learn about the mother-child relationship is to listen to mothers of children diagnosed on the autism spectrum.

Recommendations

Practice

Despite the limitations of the research study, the findings demonstrate the nature of the mother-child relationship as described by mothers of children diagnosed with ASD. Their stories have provided a view of the mother-child relationship that has not been demonstrated within the current literature. In keeping with feminist thought concerning the use of women's experiences to serve as the basis of facilitating social change (Brooks, 2007); insights gained from the mothers' stories will support the focus of the following recommendations.

Relationships within the family unit experience strain as an increased amount of attention is focussed on supporting and meeting the needs of the child diagnosed with ASD (Higgins et al., 2005), for example the marital relationship may suffer, as well as the amount of attention given to siblings may decrease (Bromley, Hare, Davison, & Emerson, 2004). The narratives accounts have informed us about the improvements needed in the area of family supports, for families of children with ASD. The literature has already proven that family support is essential (McWilliam, Tocci, & Harbin, 1998; Shannon, 2004; Trute & Hiebert-Murphy, 2007), there now needs to be a stronger practice of using the strengths that exists within families as a source to maintain family bonding and well-being. Service providers need to learn about individual families by asking such questions as: "how they work?, who are the sources of support?,, and what are the needs of each individual in maintaining and strengthening relationships within the family unit?"

Mothers of children with ASD are often at the forefront in supporting their children's development (Norton & Drew, 1994), and therefore, it is important their voices are listened to in order to develop effective services that can enhance and support the relationship development

with their children. Specifically, when it comes to supporting mothers of children with ASD, mothers need to feel safe in acknowledging and sharing their feelings, knowing their feelings will be validated, and that they will in turn receive the appropriate supports. As service providers, we need to listen to mothers when they speak, and we need to ask questions about how they feel when it comes to going through the challenges of raising a child on the autism spectrum. For example, are there any frustrations or concerns they have?, how do they feel about their role as an advocate for their children, and how do they feel about the relationship they have with the child? Taking these questions into consideration will allow service providers to work collaboratively with mothers in establishing the tools and skills mothers need to feel empowered in their mothering practices. As one mother said;

When Sean was younger, every time we would go to the developmental paediatrician, I would give an account of all that I had been doing to help Sean. The doctor would always respond "you are fantastic, Laura, you are like a super mom." This is because the onus falls on the parents. They feel that much of the progress their child is going to make is often due to all the hard work they put in. This overwhelming responsibility made me feel like I was dying on the inside, though my words and actions spoke of my competence. I was frightened nearly all the time, constantly questioning whether I was doing enough to help my child. Eventually I got thyroid disease, and I think (pointing to throat) it was really a suppressed scream for help, crying out that I felt overwhelmed and afraid. Getting ill has taught me that there is no merit in acting strong all the time, and it is really important to find safe people you can be vulnerable with. (Laura, mother of Sean)

This statement is crucial for service providers in understanding that mothers of children with exceptionalities need to be validated not for living up to ideologies of mothering, but for doing what they can within their scope. Service delivery that validates the contribution and efforts mothers are making in regard to supporting their children (e.g., to advocating for their child), no matter how small or large, can only empower mothers to continue their efforts, and feel good about their role as a mother.

Secondly, more programs and services need to be developed that focus on the impact a child's diagnosis has on the relationship of a two parent family, in order to give parents the tools they need to communicate honestly, openly, and effectively in dealing with the challenges of raising a child with an exceptionality. Mothers and fathers of children with exceptionalities, through such support, need to be reminded of the importance of working on their relationship as a couple, and as parents in order to be a source of strength for the family, and effective parents to their children.

Unfortunately most of the research on ASD is presented from the perspective of mothers, which neglects the opinions and experiences of fathers. As a result their role and contribution in dealing with the unique challenges of raising a child on the autism spectrum is not readily understood. Fathers of children on the autism spectrum may face similar, as well as a different set of challenges in dealing with their child's diagnosis. Services for fathers may need to focus on getting fathers more involved in advocating for their children, attending meetings together with the mother, also in dealing with the diagnosis. The impact of the diagnosis may affect fathers differently than mothers which warrant research in order to develop services that specifically meet their needs.

Thirdly, the development of services for adult children with ASD has been a neglected area in service delivery. Many of the mothers commented on the lack of services, and how they worry about their children's future. Future research initiatives need to focus on service needs of families of adult children with ASD, such as developing more training programs, day programs, and employment opportunities.

Lastly, changes need to be made to the structure of service delivery such that they are more streamlined and concentrated in one area to decrease the stress and frustrations of accessing

services from different providers within different locations. One mother describes her hope for the future of service delivery:

After receiving a diagnosis of autism, I think it would be amazing to have a special place where the family would go for support throughout the individual's lifespan. The family would not be discharged when the child passed through from preschool to school age, from school age to adolescence or adolescence to adulthood. Presently, families are discharged from a particular service as their child moves from preschool to school age, and once they are 18 they are discharged from pediatric care. This means families are meeting with new service providers at critical stages which are already stressful. It would be so reassuring to build relationships with staff that spanned the child's life and family's situation as the child grows and matures. I envision a holistic centre where there would be adults with autism who would act as consultants, including health professionals, dieticians, occupational therapists who would provide consultation. More importantly, it would be a place where individuals on the spectrum would be able to be with other individuals, and see role models of autistic adults who could act as mentors. (Laura, mother of Sean)

Future Research

Future research initiatives can explore how children with ASD describe their mother-child relationship as a means to further understand the relationship from the child's perspective. Secondly, research is needed to explore the impact a child's diagnosis of ASD has on the parents' relationship with one another, and to determine from parents what support they need to maintain the family. Single parents may face unique challenges as they absorb 100% of the responsibility in raising a child on the autism spectrum without the extra support to balance those responsibilities. Specific to single parents, research needs to focus on how to deliver *more* supports for single parent families. Thirdly, more inquiry is needed into the development of behaviour techniques that both focus on the mother-child relationship and incorporate the interests of the child and mother. Lastly, more research is needed that gives parents (both mothers and fathers) the platform to describe their experiences and service needs, as this may be one of the key ways to improve our understanding and to continue to develop better intervention services.

Conclusion

The purpose of this study was to explore how mothers of children with ASD describe their mother-child relationship. Through the mothers' narratives we have learned that these mothers do experience their mother-child relationship in positive ways. Mother's self-discovery continues to contribute positively to the way in which they mother their children (e.g., as an advocate), and in their experience of the mother-child relationship as a bond through self-growth. Although the mothers are faced with challenges in raising their children, they continue to experience love, joy in spending time with their children, and demonstrate a deep sense of commitment in doing the best for their children.

This research study has begun to pave the way for mother-centered research initiatives which listen to the voices of mothers as a valid way to understand their experiences, and facilitate social change. The findings of this research study are very informative; it is hoped that they are able to inform future developments of intervention services with a focus on supporting women of children with ASD in building, discovering, and strengthening their mother-child relationship. Furthermore, research initiatives can be developed based on the mother-child relationship as experienced by these mothers, in regard to exploring specific factors that may or may not mediate the development of the mother-child relationship in positive ways.

Through this research study the mothers' voices have been heard and validated in the context of a research study. Hearing maternal narratives, amongst mothers of children on the autism spectrum, are an important source of empowerment for other mothers in the early stages of the diagnosis to know that there is hope, and that in spite of the challenges they may be faced with, their mothering experiences can include the experience of joy, love, and pride in raising a

child with ASD.

Indeed, mothers of children with ASD may require extra supports in raising their children, but those supports can only make her a better mother, and possibly allow more positive moments in her mother-child relationship. Mothers of children with exceptionalities need to be encouraged in thinking that motherhood is not a universal experience, and that each mothers experience, positive or negative, of her mother-child relationship is important and valid (O'Reilly, 2004).

The narratives presented in this paper challenges all of us to broaden our understanding of mothering, as an experience that is unique to each and every mother, and to understand the mother-child relationship void of preconceived notions of what it means to be a mother, and the experience of a mother-child relationship.

Table 2:
Ainsworth Attachment Classification System (in relation to the *Strange Situation Procedure*)

Secure attachments (Type B)
In the SSP the child becomes upset when the mother leaves, however, upon reunion with the mother the child greets the mother and settles down quite easily. The child feels a sense of security with the mother and as a result explores their social worlds more, knowing the mother is there to protect. The mother's care is consistent in which she is responsive to the needs of the child.
Insecure and avoidant attachments (Type A)
In the SSP children do not demonstrate through their behaviors that they are upset when their mother separate from them. Upon reunion with their mothers these children avoid contact with their mothers. The mother does not respond consistently to the needs of the child, they appear indifferent or reject the child's demonstration of needs.
Insecure and ambivalent or resistant attachments (Type C)
In the SSP children are upset when the mother leaves. Upon the reunion with their mothers these children are hard to settle down even though contact is sought with the mother. These "...children both demand parental attention and angrily resist it at the same time. Such ambivalent behavior-displays of need and anger, dependence and resistance-is the key characteristic of this type of insecurity"(Howe, 1995b, p.80). The mother demonstrates insensitivity to the care of her child's demonstrated needs, however, she does not reject the needs of the child.
Insecure or disorganized attachments (Type D)
In the SSP children are demonstrate confusion when they are separated and reunited with their mothers. The child does not demonstrate an overall attachment pattern upon reunion with their mothers, as they demonstrate anxiety (e.g., looking away from the mother). The child does not view the mother as being able to provide comfort or safety which triggers anxiety whether the mother is present or not.

Note: Descriptions of the attachment styles are summarized from Howe, 1995b & Ainsworth et al., 1978

RESEARCH STUDY: Positive stories about the mother-child relationship among mothers of children with Autism

If you answer yes to the following three questions, you may be interested in participating in this research study:

- 1) Are you a mother of a child diagnosed with Autism?
- 2) Has it been 5-10 years since your child's diagnosis?
- 3) Do you have 45 minutes -1 hour to spare?

The research study is interested in...

- How mothers of children with Autism describe their mother-child relationship?
- Getting positive stories about the experience up to today that have shaped/influenced your mother-child relationship?

What is involved?

Interested participants will tell stories about their mother-child relationship?

Benefits

It is hoped...

- Information gathered from your stories may inform future development of intervention services that focus on supporting women of children with Autism in building and strengthening their mother-child relationship.
- That you will benefit by having your story and opinions validated in the context of a research study.
- Your stories may inspire, empower, and instill hope in mothers of newly diagnosed children with Autism about the meaningful existence of a mother-child relationship.

Location

The research study will be conducted at Ryerson University.

Compensation

Research participants will be compensated for their transportation costs (\$20). If needed, childcare arrangements can be made for the duration of the research study.

Who is running the study?

Natalia Charles, Hon. B.Sc., Master of Arts program in Early Childhood Studies, School of Early Childhood Education, Ryerson University. natalia.charles@ryerson.ca

Professor Rachel Berman, PhD, Master of Arts Program in Early Childhood Studies, School of Early Childhood Education, Ryerson University. rcberman@ryerson.ca, 416-979-5000 x7695

How do I get more information: If you are interested in sharing your stories or need more information, you can contact principal investigator Natalia Charles at 647-342-5404 or natalia.charles@ryerson.ca



RYERSON
UNIVERSITY

Interview Protocol

Filter question:

How many years (from today's date) since your child's diagnosis of Autism?

Introduction

Narrative interview (Script);

Introduction to topic: "I am interested in looking at the development of the mother-child relationship of mothers with children diagnosed with Autism. I am interested in getting stories about the experiences up to today that have shaped / influenced your mother-child attachment".

Length: Approximately 45 minutes to 1 hour

Questions: The list of questions has been devised to demonstrate the goal and direction of the study, which will be a guideline for conducting the interview in order to build or explore on what the participant have said.

- 1) Tell me your story, keeping in mind the mother-child attachment and its development between you and your child who has Autism?
- 2) What have been the joys?
- 3) What have been the challenges?
- 4) How do you feel your attachment to the child who has autism is different from your other children?
- 5) How do you feel your attachment to your child is different from that of other mothers with children who do not have autism?
- 6) Tell me about what aspects of your relationship with your child you find meaningful/enjoy the most?
- 7) What words of encouragement would you give to mothers of children newly diagnosed with autism about their mother-child relationship?

**Ryerson University
Consent Agreement**

Title: Empowering their voices; the child's diagnosis of autism and mothers positive construction of their mother-child relationship

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators/Researchers:

Natalia Charles, Hon. B.Sc., Master of Arts Program in Early Childhood Studies, School of Early Childhood Education, Ryerson University. natalia.charles@ryerson.ca

Professor Rachel Berman, PhD, Master of Arts Program in Early Childhood Studies, School of Early Childhood Education, Ryerson University. rcberman@ryerson.ca

Purpose of the Study: The purpose of this study is to explore positive aspects of the mother-child relationship specifically looking at mothers of children diagnosed with autism (in which it has been 5 to 10 years since the child's diagnosis). The research question is: How do mothers of children diagnosed with autism describe/ perceive/ construct their mother-child relationship? The purpose of the study is not to judge your parental skills, but is about exploring the positive aspects of the mother-child relationship that exists between you and your child.

Description of the Study: The following procedures will be used to collect your stories about your mother-child relationship;

- 1) The interview will take place at Ryerson University, lasting approximately 45 minutes to an hour, and will be audio recorded. Your child will not be a part of the interview; the interview will only be conducted between you and the principal researcher (Natalia Charles).
- 2) The one-on-one interview is not intended to be therapeutic or a counseling session, but is a research tool used to learn about you mother-child relationship.
- 3) The interview will begin with the following question by the principal researcher (Natalia Charles): "I am interested in looking at the development of the mother-child relationship of mothers with children diagnosed with Autism. I am interested in hearing positive stories about the experiences up to today that have shaped / influenced your mother-child relationship". Follow-up questions may be asked based on your story for elaboration or clarification purposes.
- 4) Interview Review: Another part of this research study is the opportunity for an "Interview Review," if you choose to take part in this second part of the research project, you will have the opportunity to make any changes to your written (word for word) interview, from our first personal interview. At the bottom of this consent form you will decide whether or not you wish to review your personal interview. If you choose to do an interview review, at the end of the consent form you will need to provide your contact information. Once your interview is ready for you to review, you will be contacted by Natalia Charles and an appointment will be scheduled for you to come back to Ryerson University so that you can review your personal interview, and make any necessary changes. This review will only last between 20 to 30

minutes. After you have reviewed your personal interview you will sign the second portion of the consent form.

Child care arrangements: Every effort will be made to be flexible in scheduling your interview appointment that works within your schedule and child care arrangements. Free child care will be provided if needed. Free child care will be provided by a Ryerson University student who has a background in Early Childhood Education. The volunteer will have experience and training in providing child care for children with and without disabilities. Also, the volunteer will have completed a police check within the last 6 months. Child care will take place at Ryerson University, Master of Arts Early Childhood Studies graduate lounge, in which I will provide toys, and, arts and crafts activities. The graduate lounge (Kerr Hall West, room 358) is located on the same floor as the interview location (Kerr Hall South, room 363), both are in close proximity and accessible to each other. Also, if you choose to do an interview review the same free child care arrangements will be made available.

What is Experimental in this Study: None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information, your descriptions and stories about your mother-child relationship, for the purpose of analysis.

Risks or Discomforts: It is possible that because of the personal nature of the topic, you may reflect on unpleasant memories while telling your story and become emotional. At any point during the interview you begin to feel uncomfortable in sharing your story you can discontinue participation, either temporarily or permanently. In addition a list of services within the community and emergency counselling contact information will be provided to you if you need to speak to a professional.

Benefits of the Study: I cannot guarantee, however, that you will receive any benefits from participating in this study. However, it is hoped that you may potentially benefit by having your story, opinions, and ideas validated in the context of a research study. Information gathered from your stories may inform future developments of intervention services that focus on supporting women of children with Autism in building, discovering, and strengthening their mother-child relationship. Your stories may inspire, empower, and instill hope in mothers of children newly diagnosed with Autism about the meaningful existence of a mother-child relationship.

Confidentiality: Your audio recorded interview will remain confidential. A fictitious name will be used when your interview is being analysed, and within the final paper. In the final paper, written by Natalia Charles, verbatim/direct quotes (without identifying your name or any identifiable characteristics) may be used. Also verbatim/direct quotes will be discussed with my Research supervisor (Dr. Rachel Berman) and during my final thesis defence, which will include two other professors from Ryerson University. In addition, the final paper will potentially be published within research journals so that others may learn and benefit from your stories.

Your written (word for word) interview will be saved in a word document and stored in a computer file. All data will be securely stored; computer data (e.g., recorded audio files of interviews) will be saved within a separate password protected computer account created specifically for the research project, and hard copy documents (e.g., consent forms) will be stored in a folder for each participant and stored in a locked drawer, in both cases the information will only be accessible to the principal researcher (Natalia Charles). Once the research study has finished (August, 2008), all data, including audio files (will be erased from the computer and placed on a memory stick), consent forms, and transcriptions will be stored in a locked filing cabinet. After one year from the completion date of the research study (August, 2009), all data will be discarded. Audio files will be deleted, and paper copy documents will be shredded.

Community Resources

The following resources have been provided as part of Ryerson University- Research Ethics Board ethical guidelines to minimize the risks and discomforts (as outlined in the consent form) associated with the research study.

1) Family Service Association of Toronto (FSA) FSA provides comprehensive counseling services for families that address a wide variety of issues. For more information contact: 416-595-9618, <http://www.fsatoronto.com>, address: 355 Church Street, Toronto, ON

2) Surrey Place Centre

Surrey Place Centre provides services (e.g., counseling, Behavior Therapy, Occupational Therapy, etc) to families and children with developmental disabilities. For more information contact 416-925-5141 and ask to speak to an intake worker, www.surreyplace.on.ca

Address: 2 Surrey Place Centre, Toronto, Ontario, M5S 2C2

3) Geneva Centre for Autism

Geneva Centre provides a multi-faceted delivery of services to families and children with autism. For more information contact (416) 322-7877, or intake@autism.net

Address: 112 Merton Street, Toronto, ON, M4S 2Z8

4) Kids Help Phone line

Kids Help Phone Line provides "helps adults aged 21 and older find the counseling services they need".

Office phone: (416) 586-5437 Administration

Toll -free phone: 1-800-668-6868

Fax: (416) 586-0651

E-mail: mark.letassey@kidshelp.sympatico.ca

Web site: www.kidshelpphone.ca

5) Aisling Discoveries, Child and Family Centre

Aisling Discoveries provides a wide range of services for children and their families, including counseling services. For more information contact 416-321-5464, ext. 233.

Address: 325 Milner Avenue, Suite 110, Scarborough, ON, M1B 5N1

Emergency number

Distress Centres of Toronto: Distress Centres of Toronto provide free emergency counseling 24 hours a day, seven days a week in regards to various issues callers present with. For more information contact [416-408-HELP](tel:416-408-HELP) (4357). For general information: 416-598-0166 <http://www.torontodistresscentre.com>

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