Acknowledging Mother’s Lived Experience of Raising a Child with Autism: A
Phenomenological Inquiry

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Abstract

Autism is one of those human ambiguities that forces vigilant open-mindedness – sometimes this open-mindedness comes without choice, for example when you become the mother of a child with autism. Recent reports indicate that Pervasive Developmental Disorders affect 1 in 150 children (Centre for Disease Control and Prevention, 2007). This also means that there are many families caring for children with autism. The purpose of this research was to explore the day to day lived experiences of mothers caring for a child with autism.

With a drastic increase in children diagnosed with autism, and very little research on mothers themselves, assisting in articulating lived experiences from mothers themselves seemed like an acceptable first step. Mothers were asked to journal for a period of one month, once a week, as well as participate in a focus group. Findings from both of these techniques were analyzed using underpinnings from Amelio Giorgi and Max van Manen. General findings indicate that mothers present poignant narratives about living with their child. It becomes clear that mothers are stressed, and live a complicated and often contradictory existence. Many days are fraught with struggle, anticipation, watchful eyes, judgment and guilt. There is a constant battle waging; the one within themselves, and the one with an uninformed and uncooperative public.

Given that this research contributes to an extremely small body of qualitative research on mothers, future research should continue to gain insight from mothers, without classifying or categorizing their words. Their words speak volumes. Professionals may know autism, but mothers know their children.
Acknowledgements

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“Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute -- the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look "normal" but his behavior can be perplexing and downright difficult” (Notbohm, 2005).

Working as a respite worker, therapist, support facilitator, camp coordinator and at times ‘stand in parent’ for children with autism has given me a unique perspective on the disability itself, and the familial, educational, bureaucratic, and societal issues that affect children and their families. In part, I suppose I became frustrated with the lack of support and understanding and the general dismissal of the issues that face families on a day to day basis; on another level, with the treatment of children with autism and the rigorous training that goes into sculpting them to be acceptable ‘bodies’. This is not a thesis about my frustration with the system, however, these frustrations did lead me to the “what now?” question.

Working with children leads to working with families, or more often with mothers. I heard and witnessed their daily frustrations over trivial events, which to most mothers would never be a blip on their radar, but to these mothers these “trivial events” serve as a daily reminder that their life is different, their child is different, and therefore their family is different. Do we as a society support these mothers? Do we ask them what would make their life easier? Do we as ‘professionals’ value their opinions? Do we strive to understand their experiences to better their life and the life of their child? Most of the time we compartmentalize how many mothers are depressed, stressed, and generally
unhappy with their lives. Rarely, do we let their experiences speak through their own 
words. Schuntermann (2002) supports the importance of asking mothers about their 
experiences when he states, “Families of children with pervasive developmental disorder 
(PDD), in particular, may present with poignant narratives about their (and others’) ways 
of adapting to their child’s special needs” (p.16).

There is little argument that raising a child with autism is challenging to say the 
least. However, what about this experience is so challenging, the most challenging in fact 
than any other developmental disability according to past research (Tobing and 
Glenwick, 2006). Given the developmental trajectory of autism, parents caring for 
children with this disorder are in a constant state of adaptation and coping. According to 
Schuntermann (2002) the uneven developmental patterns typically seen in children with 
autism are confusing and difficult for parents to adapt to. Parents are continually faced 
with the challenge of finding services to assist their child, while maintaining their role in 
all other aspects of their life. Given that autism is also not widely understood by the 
outside public many parents continue to feel judged as a result of their child’s confusing 
behaviour. It is not surprising then that Tomanik, Harris, and Hawkins (2004) and Tobing 
and Glenwick (2006) found that parents of children with autism face higher stress than 
parents of children with other developmental disabilities and those of typical children. It 
also appears that stress happens to be greater for mothers, as they typically assume a 
greater role, as primary caregiver, in caring for the child both physically and emotionally.

Autism Spectrum Disorders (ASD’s) are one of the most common developmental 
disabilities. According to a recent Canadian study, the prevalence rates of autism 
spectrum disorders are 1 in 165, making them more common in childhood than Down
syndrome, cystic fibrosis, and cancer (Kabot, Masi, & Segal, 2003). In Ontario alone, there are approximately 70,000 individuals living with autism (Autism Ontario, 2006). The most frequently referred to definition of autism can be found with the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR). According to the DSM-IV-TR, autistic disorder is one of several pervasive developmental disorders (PDDs) that are caused by an inhibited central nervous system leading to disordered development (Kabot et al., 2003).

Generally, children with autism have difficulty in communication and social interaction. Often atypical behaviours such as unusual responses to sensation, repetitive movements, and insistence on routine or sameness are evident (Neisworth and Wolfe, 2005). Autism is apparent between 18 and 36 months of age, although it is often not formally diagnosed until much later leaving parents baffled about their child’s atypical behaviour. The specific behavioural manifestations of autism are often unique to each child, however, what is not unique is the confusing and unpredictable nature of the disorder.

Past study has shown that mothers are stressed, while uncovering many of the factors that seem to be affecting maternal stress, but very little research has asked mothers what is happening in their day to day lives (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Fong, Wilgosh & Sobsey, 1993; Gray, 2002, 2005; Hastings et al., 2005; Herring et al., 2006; Schunerman, 2002; Tobing & Glenwick, 2006; Tomanik, Harris & Hawkins, 2004; Weiss, Sullivan & Diamond, 2003). Research tends to focus on quantitative findings with little emphasis on what mothers are actually feeling and experiencing (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Fong, Wilgosh & Sobsey,
1993; Gray, 2002, 2005; Hastings et al., 2005; Herring et al., 2006; Schuntermann, 2002; Tobing & Glenwick, 2006; Tomanik, Harris & Hawkins, 2004; Weiss, Sullivan & Diamond, 2003). Hopefully, uncovering what may seem like the monotonous day to day experiences will only help to reinforce what we already know about autism as well as provide more detailed information about mothers’ knowledge of their child’s disorder. Given that children spend a lot of time with their parents, many times more with their mothers, it is mothers who can provide a detailed account of what autism is like when you live with it. As a result, this research study looks at the day to day lived experiences of mothers who are raising a child with autism.

Phenomenological inquiry, a technique used to describe and uncover meaning, will attempt to articulate the day to day lived experiences of mothers who have children with autism (van Manen, 1990; Jackson, 2003). Using a reductive, recursive process the focus will not only be on understanding the day to day lives of mothers who have children with autism but also on working as a team to develop a greater understanding of what can be done better to manage or solve issues occurring as a result of having a child with autism. By articulating these lived experiences a narrative will develop around the essences of experiences occurring in mothers’ lives. By better understanding areas of strength and weakness, and gaining insight into this particular phenomenon, mothers are better served which bi-directionally serves the needs their of children.
Literature Review

*Historical Insights on Autism Spectrum Disorders*

Prior to 1943 when autism was recognized as a distinct psychological disorder, what we now know as autism was described by Jean Marc Gaspard Itard in France and Josh Haslam in England when they told the story of Victor, a wild boy found in a forest in France (Dumas & Nilsen, 2003). Within Kanner’s own writing he describes the story of Emerentia, a child with peculiar psychotic-like behaviour. The father and stepmother offended by the child’s behaviour sent her to live with the local minister, who was known for his rigid orthodoxy. The child later died after being subjected to a multitude of inhumane remedies, on account of her ‘psychotic behaviour’ (Kanner, 1962). Many of the symptoms were characteristic of what is now diagnosed as autism.

Despite earlier documentation, autism was not recognized as a distinct psychological disorder until documented by Leo Kanner, a psychiatrist and physician in 1943. In the same year Hans Asperger of Vienna, Austria described children using the term ‘autistic’. It has been suggested that both were unaware of the other when describing the characteristics of autism (Lyons & Fitzgerald, 2007).

In 1943, Kanner described 11 children with a condition that differed from anything he had seen so far. Initially he believed these children were suffering from, “an inborn disturbance of affective contact” (Fein, Robins, Liss, & Waterhouse, 2001). Later he noted that these children were experiencing, “extreme autistic loneliness” as they exhibited an inability to relate to themselves and others (Dumas & Nilsen, 2003, p.87; The Lancet, 2004). The term autism comes from the Latin word *auto*, which means self. Kanner described the physical, emotional, and psychological characteristics of these
children, as well as detailed descriptions of their families. Kanner defined autistic children as children who exhibited (a) a serious inability to develop relationships with other people before 30 months of age, (b) difficulty in development of normal language, (c) ritualistic and obsessive behaviours, and (d) potential for normal intelligence (Lovaas, 1987). In his description of the child’s parents they were described as highly intelligent, with college degrees, and distinguished professions. This lead Kanner to believe that autism must be biological, not psychological in nature. However, in later documentation Kanner blamed family factors, namely the child’s cold and rejecting mother as a cause of autism. It was concluded that in many, if not all cases, the children’s symptoms represented, “a primitive attempt to protect themselves from the extremely harmful effects of parental emotional refrigeration” (Dumas & Nilsen, 2003, p.89, Fein et al., 2001, Hill and Firth, 2003). Since Kanner’s initial documentation of autism, the characteristics and criteria for diagnosing autism have changed markedly, however, the initial psychological perspective had a major influence on researchers, clinicians, and maybe more importantly, mothers.

*Developmental Characteristics of Pervasive Developmental Disorders*

Autism is one of a group of neurological conditions defined as pervasive developmental disorders (PDD) or also commonly referred to as autism spectrum disorders (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005). Current definitions of autism are provided by the Diagnostic and Statistical Manual-Fourth Edition (DSM-IV-TR) of the American Psychiatric Association (APA). The disorders included within the umbrella term of PDD include: (1) autistic disorder, (2) Asperger’s disorder, (3) childhood disintegrative disorder, (4) Rett’s disorder, and (5) PDD-not
otherwise specified (Fein et al., 2001). Although these categories differ markedly in onset, etiology, symptoms, long term trajectory and treatments, all five share a core deficit in forming relationships and communicating (Kabot, et al., 2003). Autism, Asperger’s and PDD-NOS, are normally diagnostically grouped together under the broad term, autism as they hold similar symptomologies, while Rett’s disorder and child disintegrative disorder differ quite substantially. For this reason, only mothers who have children diagnosed with autistic disorder, Asperger’s disorder and PDD-NOS will be included in this study. Briefly, Asperger’s disorder includes children and adolescents who have social impairments, as well as display repetitive and restricted behaviours, but who have normal language and intellectual functioning. The term PDD-NOS is used when a child demonstrates impairments in the three areas of functioning but not enough to be diagnosed with autism (Fein et al., 2001).

Autism is said to be on a spectrum because all of the components are related to one another conceptually but differ in severity (Tager-Flusberg, Joseph, & Folstein, 2001). According to the DMV-IV-TR, in the majority of cases the symptoms of autism appear early (in infancy and early childhood), are apparent across different areas of functioning, affect the child’s entire developmental trajectory, and are often comorbid with developmental delays or serious medical conditions (Dumas & Nilsen, 2003).

Socially, children often have difficulty with non-verbal communication such as eye contact, facial expression, and body posture, while also lacking mutual attention behaviours (pointing, and looking where someone else is pointing). Children with autism are unlikely to seek out physical or emotional contact and therefore are often unable to
develop peer relationships that are appropriate to developmental level (Dumas & Nilsen, 2003; Matson, Matson, & Rivet, 2007).

Communication and play delays can include poorly developed language, lack of reciprocal conversation skill (for one's age) and language that is stereotyped or echolalic (Fein et al., 2001). Chan, Cheung, Leung, Cheung, & Cheung (2005) noted that almost 50% of individuals with autism do not develop functional or communicative language during their lifetime. Many people with autism are unable to communicate verbally and non-verbally. If language is present it is often stereotyped and repetitive, with the person being unable to initiate or maintain a conversation. Tager-Flusberg et al. (2001) found that, “conversational deficits are related to problems in understanding that communication is about the expression and interpretation of intended meaning rather than the literal meaning” (p.24).

Repetitive and restricted behaviors are also commonly found in children with autism. Many children have very limited interests, are inflexible in terms of routine and ritual, and may perseverate on preferred activities or topics (Fein et al., 2001). Children who are removed from undesirable activities or placed in an unknown situation often display maladaptive coping behaviours. Commonly children with autism will also display repetitive motor movements, such as hand flapping, or preoccupations with parts of objects, such as spinning the wheels of a car repeatedly. Given the large spectrum of possibilities, every child with autism is unique, requiring different adaptive techniques, environments, and treatments. Intellectual functioning tends to highly relate to the amount of support a child requires, as well as how their social and communicative deficits manifest themselves (Fein et al., 2001).
Diagnostic Criteria

Although not used to select participants within this study, the criteria that an individual must meet to be diagnosed with a pervasive developmental disorder is important to understand the manifestation of symptoms, and to provide readers with a better understanding of the often confusing characteristics that surround an autism diagnosis. As noted above, PDD’s are characterized by qualitative impairments in social functioning, verbal and nonverbal communication skills, and repetitive and stereotyped patterns of behavior (Tager-Flusberg, 1999; Hill & Frith, 2003; Lovaas, 1987, Kabot et al., 2003). The DSM uses a set of criteria, where the child must exhibit a certain number of symptoms within each domain. Given that autism is a spectrum disorder, including individuals of all intelligences, ability, and severity, a wide range of criteria must be utilized to efficiently and correctly diagnose children with autism.

Generally, the child must show a total of six (or more) items from sections one, two and three, with at least two from one and one each from two and three. Category one encompasses qualitative impairments in social interaction, while category two looks at qualitative impairments in communication. The last category includes restricted and stereotyped patterns of behaviours, interests, and activities (American Psychiatric Association, 2000). Examples of behaviours that fall within each category have been included in the section entitled, Developmental Characteristics of Pervasive Developmental Disorders. Children must also show delays or abnormal functioning in at least one of the following areas, with onset preceding age three: (1) social interaction, (2) language used in social communication, (3) symbolic or imaginative play. Last, the
disorder cannot be better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder (American Psychiatric Association, 2000).

Sigman, Dijamco, Gratier, and Rozga (2004) discuss that a current major goal of researchers is to better identify the core deficits children, adolescents and adults experience, a challenging task when we consider the variability among people who are affected by autism. As mentioned previously, autism, Asperger’s and PDD-NOS share some core features, and are often confused by definition and diagnostically with one another. Given that Rett’s disorder and childhood disintegrative disorder differ symptomatically they are rarely confused with the other disorders (Kabot et al., 2003).

Typically areas of impairment are assessed through the Autism Diagnostic Interview-Revised (ADI-R) the Autism Diagnostic Observation Schedule-Generic (ADOS-G), the Autism Behavior Checklist (ABC), and the most commonly used instrument, the Childhood Autism Rating Scale (CARS). Currently, children are diagnosed reliably by age 3 and sometimes even by age 2 (Bryson, Rogers, & Fombonne, 2003). However, evidence indicates that most children are not diagnosed until after age 4, typically at least two years after parents have sought assistance. Interestingly, and a strong indicator also of familial stress most children are seen by at least 3 professionals before a diagnosis is made. According to Bryson et al., “the long delay between parents’ initial concerns and eventual diagnosis also postpones appropriate intervention, which, coupled with evidence of its effectiveness, leaves parents with the sense that precious time has been lost” (2003, p.507).

Prevalence and Etiology

Epidemiological studies of autism began in the mid-sixties in England. The
earliest prevalence rates were found to be 4-5 cases per 10,000 (Lotter, 1966, as cited by Filpek et al., 1999). In the 1970's it was estimated that autism occurred in 4 in 10,000. Current research suggests that autism occurs in 20 in 10,000 (Fombonne, 2003).

Explanation for the increased incidence include a greater awareness of early symptomology by professionals, and parents, increased diagnostic work ups, and the existence of presently unknown environmental factors (Kabot et al., 2003). It is also important to note that autism typically occurs three to four times more frequently in males than females (Filipek et al., 1999).

Researchers have found a genetic link to autism; however, it is one that is poorly understood. Presently, Chromosomes 7 and 15 are believed to be defective and relate to PDD’s. Studies that have looked at the genetic abnormalities of children with autism do find differentiation from typically developing children (Dumas & Nilsen, 2003). Studies conducted by Iverson (2001) and Courchesne et al. (2001) found an abnormal capacity for serotonin synthesis within the brains of children with autism, as well as abnormalities within the limbic system. Researchers continue to attempt to link behavioural symptomology to neurobiological causations (Kabot et al., 2003, Zwaigenbaum et al., 2005).

Most epidemiological and etiological research surrounding autism comes with conflicts, as evidenced by Kabot et al. (2003) and Zwaigenbaum et al. (2005). Most researchers do agree that autism is caused by a dysfunction in the central nervous system, however, conflicting opinions surround the relationship between brain dysfunctional and manifested behavioural characteristics. According to Kabot et al. (2003), “authorities do agree that autism can be defined at three different interdependent levels: as a neurological
disorder related to brain development; as a psychological disorder of cognitive, emotional, and behavioral development; or as a relationship disorder in which there is a failure of normal socialization” (p.26). Furthermore, both prenatal and postnatal environmental factors have been identified as triggers in the onset of autism (Kabot et al., 2003).

**Comorbid Conditions**

Autism is allied with a number of comorbid conditions, all which complicate its diagnosis and treatment. Hill and Firth (2003), Kabot et al. (2003) Fein et al. (2001) and Dumas and Nilsen (2003) note that autism is commonly associated with mental retardation, attention deficit disorder, motor in-coordination, Tourettes’s syndrome and psychiatric symptoms such as anxiety and depression. In a study undertaken by Fombonne (2003) it was noted that prevalence rate of mental impairments in children with autism was nearing 70% (1700/2400 participants). Thirty percent of these children had mild to moderate delays, while 40% had severe to profound delays. Croen, Grether, and Selvin (2002) approximated that mental retardation occurs in 75% of children with autism.

It has been proposed that approximately one third of children with autism also develop seizure disorders, starting in early childhood or adolescence. Fragile X syndrome has been found in approximately 10% of autistic individuals; more commonly in males. A link was also found between obsessive compulsive disorder (OCD) and autism (Kabot et al., 2003). These conditions present another major hurdle in caring for children with autism.
Raising a child is a demanding task for any parent, but for parents of children with autism child-rearing brings a whole set of new challenges. Given the broad scope of issues that children with autism face, intensive early intervention is highly recommended. Evaluating and choosing among the diverse treatment options can be an overwhelming task for parents. One of the most important features of most interventions is that they are consistent and generalizable across all environments, and more importantly that they have the goal of assisting the person to become a fully functioning member of society (Kabot et al., 2003).

Currently, intensive behavioural interventions (IBI) which found their principles on applied behavioural analysis (ABA) is prominent. IBI works to increase appropriate behaviours and decrease inappropriate behaviours through the principles of reinforcement and punishment. The National Institute of Child Health and Human Development lists a number of treatments currently being used: biomedical treatments such as vitamins and minerals, gluten-casein free diet (GFCF), floortime, occupational therapy, craniosacral manipulation Picture Exchange Communication System (PECS), sensory integration therapy, speech therapy, TEACCH, holding therapy and verbal behavior therapy (Autism Speaks, 2009; Kabot et al., 2003).

Most of these treatments support intensive interventions for children with autism. Although treatments vary in terms of how they approach treating children with autism, they all seem to agree that treatment beginning early that focuses on intensive, individualized, long running treatments work best (Bryson et al., 2003, Eikeseth, Smith, Jahr, & Eldevik, 2002). Treatments that focus on these goals have assisted children with...
autism in making significant gains on standardized tests of cognitive, language, adaptive, and academic skills (Eikeseth et al., 2002). Research suggests that the earlier the treatment begins, the better outcome, as younger children have more behavioural and neural plasticity than older children do.

Typically, these therapies demand upwards of 20-25 hours of weekly therapy. Most clinicians recommend that children are enrolled in behavioral interventions for up to 40 hours a week, beginning before age 4 and lasting for it least 2 years, but often longer (Weiss and Delmolino, 2006; Lovaas, 1987). Weiss et al. (2006) found that 50% of children who participated in such programs showed significant increases in IQ and were able to be placed in regular education classes with little to no support. Additional studies have reported that half of the children receiving 40 hours of therapy achieved normal educational and intellectual functioning (Weiss et al., 2006). These results were found within both center and home based programs. Although this study does acknowledge the success of intensive behavioural therapies, they are discussed primarily to show the commitment required from parents. Outcomes derived by Bryson et al. (2003) found that young children's abilities could be significantly enhanced when carefully planned and delivered instructions were utilized.

To date, there is no curative treatment for autism. Psychopharmacological treatments can be utilized in cases where maladaptive behaviours are unmanageable, however, these do not cure the autism, rather they treat the symptoms of autism. Bryson et al. (2003) established that medication should be used sparingly, only when all other options have failed, and as infrequently as possible before age 5.
Maternal Stress and Autism

The developmental trajectory of autism often involves confusing developmental spurts, lags, and regressions that are unpredictable and difficult to deal with (Schuntermann, 2002). Many parents may not know how to relate to their child, especially when the child exhibits unwanted or maladaptive behaviours (Schuntermann, 2002). Gray (2005) also notes that autism is one of the most stressful of childhood developmental disabilities because of the problems with communication, emotional affect, and antisocial behaviours exhibited by the children. Many parents go through a period of ambiguous loss, as they realize the child they thought they’d have is not the child they must live with (O’Brien, 2007). As previously mentioned, levels of parental stress in mothers of children with pervasive developmental disorders have been found to be extremely high as a result of many interrelated factors (Tobing & Glenwick, 2006; Tomanik et al., 2004; Herring, Gray, Taffe, Sweeny, & Einfeld, 2006; Hastings, Kovshoff, Ward, degli Espinosa, Brown, & Remington, 2005; Weiss, Sullivan and Diamond, 2003, Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

Weiss et al. (2003) found that mothers of developmentally delayed children reported more problems relating to personal freedom, time, health and mood, and a greater sensitivity to their child and the community’s reaction. It seems that mothers often exhibit guilt, physical symptoms, and tension about their parenting abilities much more than fathers or parents of typical children. Decisions around treatment often overwhelms parents as they are continually struggling to find what is appropriate treatment for their child, while dealing with the continual changes that come with a diagnosis of pervasive developmental disorder.
It is important to note that intensive interventions require extensive commitment from parents. Parents are required to drive children to and from their therapies, sometimes attending two or more different therapies in a day, as well as participating within each therapy's program. A diet change also requires a multitude of changes, in terms of stores a parent can shop at (often out of the way and very expensive) as well as the time commitment required to make different dietary options. Treatment is never a quick fix, and often requires a dramatic life change for both parent and child.

Researchers have generally agreed that parents of children with disabilities experience 'courtesy stigma' a term coined by Goffman as parents of children with disabilities are associated with a stigmatized group, but not as a result of any qualities they hold on their own (Gray, 2002). For parents of children with autism, this stigmatization may be more difficult because often children with autism do not physically look like they have any 'problems' but rather act in ways that make them stand out negatively. Most parents, including those with typical children, have probably received the awkward stares when their child 'misbehaves' and strays from common conceptions of the well behaved child. This idea of seen but not heard still remains at the heart of many families, however, this is not typically a quality that applies well to children with autism.

Cashin (2004) explores the experience of parenting a child with autism with the hypothesis that this experience changes the parent's sense of self. Cashin (2002) also discusses a study done by Fong, Wilgosh and Sobsey (1993) which looks at the experience of parenting an adolescent with autism. According to Cashin (2004) the characteristics of autism often permeate the parent's sense of self, pulling them into a
vortex life state. Phenomenology was used to uncover the lived experience, while also exploring how the Dasein or state of being in the world is affected. Nine parents of children, ranging in age from four to ten with a diagnosis of autism or Asperger’s disorder were interviewed. Four focus groups were also conducted. It was found that parenting a child with autism does have profound effects on the self. Given that autism affects all areas of functioning, changing with developmental age, autism typically affects both short and long term family projects or goals. Cashin (2004) discusses that parenting a child with autism is not unlike a vortex as changes are enforced and happen in a pervasive and progressive manner. Parent’s social contact with the world is altered, sometimes even terminated, creating a new and often restricted way of being, one that was not chosen by the parents themselves. This creates an ongoing feeling of anxiety and exhaustion.

Six different narratives developed through parental interviews and focus groups: less spontaneity, less social contact, less things, less self, positives, and patience. Parents described feeling less spontaneous because both their conversations and activities with their children, spouses and extended family had a structured routine that rarely deviated from the usual. Every event took the same path, and often had the same ending. This routine often caused frustration for the parent, because they could not always understand the child’s obsession with routine and sameness. Clearly, they were also frustrated with the boring, rigid structure their lives began to take.

Decline in social contact occurred as a result of the challenges faced prior to and during a social outing, and also the challenge in introducing your child and their behaviours to your social circle. Social outings can often end in behavioural disturbance
for the child, and stress for the parent. Obviously, this causes emotional and sometimes even physical distress. As a result, parents stop going out as frequently to avoid the judgments of others. Parents again raised the concern that because autism is an invisible disorder, people are more apt to judge, deciding that the child is misbehaving as a result of poor parenting, not as a result of an impairment. Parents also expressed having less (sic) things, out of both financial constraint, and the continual damage of personal belongings and furnishings. Most parents with children who have autism would agree that it permeates all areas of family life and decreases the parent’s self. Little time or energy was left for the role of the parent, spouse or that of personal fulfillment. The self often shrunk to the role of ‘parent of autistic child’ only.

The themes positives and patience were described in a related manner. The triumph of connection was evident; however, frustration and exhaustion often came prior. Connecting with a child with autism can be a challenging task, but was described as comparable to winning the lottery, and a time of pride. Patience was often a developed trait, however, an important if not required skill to maintain sanity.

Beyond this one study, mothers are very rarely asked what is happening in their day to day experiences of raising a child with autism. Interestingly, past researchers have noted that, “Families of children with pervasive developmental disorder (PDD), in particular, may present with poignant narratives about their (and others’) ways of adapting to their child’s special needs,” and yet only one research study was uncovered that actually asked parents about some of the struggles and joys of living with their child (Schuntermann, 2002, p.16). Schuntermann (2002) goes on to discuss in further detail
that these narratives may serve parents themselves, but can also inform professional and community services.

Acknowledging Present Research – Incorporating Alternative Models of Development

As was seen in Cashin (2002) parents can provide detailed, comprehensive and meaningful narratives that may serve as both a cathartic experience for them, and as an informative piece for the community. Similar to Cashin (2002) in this study phenomenology will be undertaken as a methodology, however, Max van Manen’s (1990) hermeneutic approach will be combined with Amedeo Giorgi’s (1986) descriptive approach. These methods require a careful attunement to the participants’ words, an understanding of the way we come to know something. Reading, re-reading, writing, re-writing are at the forefront of this approach.

Connolly, Parsons, Craig and Posavad (2009) discuss Giorgi’s (1986) sequence of writing that includes: (a) reading to get a sense of the whole (b) separating complex phrases into meaning units (c) re-phrasing the participants language into more inquiry based language (d) creating descriptions that are honest to the participants words but that also reflect and connect to the research question. van Manen (1990) encourages the use eidetic attunement which helps to hone in on strong words and phrases, and lifeworld existentials such as body, space, time and relation. Attunement to these categories help to structure the re-writing of the participants’ words as well as poetic engagement with the writing. I believe both of these approaches will create a more comprehensive approach that will serve the participant and the researcher in looking at the specific characteristics of the mother’s experience.
In this approach, human beings are understood primarily as knowers (Laverty, 2003). In contrast to Cashin (2002), journaling will be used instead of interviews as it is believed that they may provide a more intimate forum for personal disclosure. Last, only mothers will be studied, as past research has pointed out that they more often that not, serve as the primary caregiver, and are therefore able to assess the experience of actually parenting a child with autism more effectively.

Notably, research has uncovered many of the factors that seem to be affecting maternal stress, however, there is a strong emphasis on quantitative findings with little focus on what mothers actually experience and feel on a day to day basis. Without discounting the importance of these findings, qualitative methodologies can only enhance and deepen our understanding of what mothers feel is happening in their day to day lives that is of both of stress and of joy. A qualitative approach will allow for a more robust description and understanding of what mothers of children with autism experience on a day to day basis. No research to date has examined how mothers can contribute to decreasing maternal stress, and provide clinicians, therapists and people both in and outside the autism community information on what mothers need. Given that mothers are the only ones who can write about their experiences, and therefore what they think they need, the potential for both new information and resources is substantial.

Alternative Inclinations about Autism: A Complication of ‘Truths’

Disability and Conceptions of ‘Normal’ Re-defined. Psychological science and the majority of current ‘truths’ constructed about autism are essentially a by-product of modernist thinking. To be more specific, autism is often seen as a pathological problem in need of treatment. Autistic people are typically not seen as effective, normatively
engaged contributors to society. Instead, they are ‘treated’ with intensive behavioural therapies, sensory therapies and dietary remedies. If we had a different conception of what autism is and what autism needs, might the spectrum of interventions also be broadened and deepened?

I am not attempting to eradicate modernist notions of autism – I see their benefit to children and families. I am, however, proposing alternative constructions of both autism and mothers who live with children with autism which can only enhance and deepen our understanding of current spectrum discourses. Possibly, it can help to illuminate where future discourses should go, and how a change in thinking and conceptualization may assist children and their families living with a diagnosis of autism spectrum disorder.

Normality – do we actually know what it is, or are we just running from conceptualizing possible varieties of legitimate ways of being in the world? Social psychologists look at how people’s thoughts, feelings and behaviours are influenced by the actual, imagined or implied presence of others (Shaffer, Wood, & Willoughby, 2005). The idea that others may be imagined or implied suggests that we are susceptible to social influence even when no other people are present, such as when sitting outside or following internalized cultural norms (Shaffer et al., 2005). These invisible guidelines of behaviour are present even when no one is watching perpetuating the appropriate way to behave and encouraging normative behaviour even when only in the presence of oneself.

Whether we admit it or not, most of us, if not all of us strive to abide by various normative cultural expectations. The second a child is born he/she is measured, weighed, and ranked to calculate his/her status as a ‘normal’ human being. Davis (2006) believes
that in order to understand the disabled body, we must also understand what is considered the normal body. The problem lies in the societal construction of disability as a problem, and a problem that resides solely individually within a person, not within society itself. By doing this the disabled person, and by association often their families are placed outside the norm, rendering them different, or ‘othered’. A contradiction to this idea is that of someone with quadriplegia. Obviously, society cannot cast this person as a quadriplegic, however, they can create boundaries that further hinder the person’s development as a result of being disabled, just as they can when someone has autism.

Wendall (1996) believes that when we ‘other’ a person or a group of people, we group them together as the objects of our experience rather than as subjects of our experience; people who we might identify with. As a result, they are seen as symbolic of something else, most often something we reject and fear (Wendall, 1996).

Foucault, in *Madness and Civilization* highlights this point well when he explained, “how madness or insanity came to be a powerful concept and social reality used for aggregating, defining, and incarcerating a specific (but historically, ever-changing) population of people. This specific history serves as an informative template for understanding how persons are subjugated and oppressed through classification as “other,” examples of lesser forms or humanity that differ in substance and character from “normal” (Danforth, 2000, p.366).

The social authority of doctors, researchers, and other professionals who deem ‘madness’, or disability comes in part from their cognitive ability with their profession, and in part from their positions within powerful institutions (Wendall, 1996). Irving Zola (1972) states that, “medicine is becoming a major institution of social control, nudging
aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts” (Wendall, 1996, p.118).

As a result the cognitive and social authority of medicine validates or invalidates how our body experiences the stress, struggle, and tension we experience within our own lives. In many ways the authority of medicine overrides our own beliefs, and needs, and renders us helpless in caring for our own and in this case, our children’s bodies. Medical and scientific descriptions of disability are frequently third person accounts of how a person should be treated, which can eliminate our authority over our own bodies. Wendall (1996) notes that women, the elderly, and men who are poor, old and disabled are routinely treated without authority. Since, it is most often women who are acting on behalf of and taking care of their disabled child, they find themselves in a very compromising position; both woman, and mother of a disabled child rendered vulnerable to this kind of treatment.

What is normal has been changing with every historical period. Social problems are often constructed within particular times, and sometimes as a byproduct of the western medical system. That is not to say these problems are created deliberately by western medicine. The medical system is very good at focusing on the medical needs of their patients but when that need falls out of the system they are often unable to respond appropriately. (Lane, 2006).

Oppression often occurs when power relations between people and groups create domination and subordination, superiority and inferiority. Within this group there are people who hold power, and those who lack control, and therefore power (Charlton,
By relating this notion specifically to disability it is easy to see how dominant classes and cultures everywhere impose on people with disabilities the normality of their authority and advantage (Charlton, 2006). The most obvious example in relation to autism is schools of behavioural control and intervention that use reinforcement systems of tokens, points, and levels to encourage appropriate behaviour (Danforth, 2000).

A task for developing a new understanding of disability is the attempt to create new ways of thinking about the abnormal (Davis, 2006). People with autism seem to hold two places in society: one, the severely disabled, hand flapping, non-verbal, drooling body and two the abnormally intelligent, gifted, and contributor to society. Those within the first realm are often removed from dominant culture, hindering their role as citizens. The problem also lies within the fact that there is a very wide range of what constitutes autism. Many of these people are not severally incapacitated or gifted. Recognizing and assisting these people is just as important.

*The Social Construction of Disability: The Medical and Social Body.* The medical model of disability labels people by symptoms and as a result often defines people as either able bodied or disabled. However, according to Simi Linton (2006) disability does not require medical language for symptoms or diagnostic categories. Terms, according to Linton are used to position people in ways that are socially and economically suitable for society. Susan Wendall (1996), a teacher of philosophy and women’s studies diagnosed with myalgic encephalomyelitis would agree with Linton. Wendall (1996) also notes that disability cannot be defined in purely biomedical terms because social arrangements and expectations contribute to impairment and disability as well as their absence.
Although there are many benefits to medical jargon, for Linton the harms clearly outweigh the benefits. Medical treatments have increased the well being for people living with disabilities, and have prevented many diseases and impairments. However, in opposition the medical model often defines deviation from the norm as a pathological condition that is only of personal burden and tragedy. This process can devalue, and sometimes disregard the social processes and policies that limit disabled people’s lives (Linton, 2006).

The social constructions that contribute to disability range from the social circumstances that create illness to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies. These processes create disability as the person’s only identity which further separates their body and space from mainstream society (Wendall, 1996). Often, disability occurs because of the unwillingness of ‘paradigm’ citizens to create ability among people who do not fit the mental or physical profile of the able bodied.

*Repositioning Children and Mothers within Disability Studies.* Research tends to focus on the burden and hardship of raising a child with autism, with little emphasis on how this experience may have affected mothers positively. Given that phenomenology does not presuppose its data, and therefore asks a question open enough to both options, mothers are able to determine what their story should encompass – positive, negative and everything in between. The focus of the research will begin to take shape as a result of what mothers themselves have reported feeling.

Mothers of disabled children occupy a complex, contradictory and marginal position within disability studies. This occurs because mothers are not disabled; however,
maintain a place within the disabled world because of their child’s diagnosis (Ryan & Runswick-Cole, 2008). A major US survey found that the average woman spends 17 years caring for children and an additional 18 years caring for ill or disabled relatives (Wendall, 1996). Mothers who care for children with disabilities confront drastically different demands than mothers of non-disabled children. For example, they routinely interact with medical professionals and institutions where they must advocate for their child to get appropriate services. Despite the increase in interactions, “the status of mothers is frequently so reduced that their knowledge of their own children is ignored or discounted” (Wendall, 1996, p.141). It is surprising that the knowledge mothers hold is overlooked given that they are the child’s mother. Does this happen with mothers of typical children? I would argue to a much lesser degree than those with children with disabilities.

Wendall (1996) explains that medical professionals often blame parents (especially mothers) for their child’s disability, for their failure in treatment and for the children’s incapability to become more autonomous. “Mothers of children with disabilities are subjected to more institutionalized control, more bureaucratic monitoring, and more social judgments of the quality of their caregiving than mothers of children without disabilities” (Wendall, 1996, p.141). At the end of the day the mother still must maintain a relationship with their child despite the fact that they often ‘force’ their children to take unwanted medicines and perform undesirable and sometimes painful therapies. Sadly, mothers are often the scapegoats of a society that fails to provide adequate and appropriate services for people with disabilities, and yet increasingly holds them to a higher, unattainable standard of ‘normalcy’.
The disciplines of normality, like those of femininity demand control of the female body. These standards are not only enforced by others but internalized. It only makes sense then that mothers raising a child with autism would become more aware of these standards as they begin to fall further and further outside of them. Obviously, the mother does not have the disability; however, this does not exclude her from the group she now becomes a part of. For many of us, our proximity to the standards of normality are an important aspect of our identity. No one wants to be an outsider, different, misunderstood. However, we are unlikely to notice (or acknowledge more likely) this until our ability to meet the standards in threatened in some way (Wendall, 1996).

Everyone wants to appear normal, whether they are or not. According to Wendall, (1996) those who are abnormal are a constant reminder to those that currently make the cut that they might fall outside. When you have a child diagnosed with autism, you don’t choose to fall outside, but you do, and in reality there is no way back in to the inside. You can control your behaviour, but you can’t necessarily control your child’s.

*Post-Modernism.* Post-modernism assists in this process, as it supports a patchwork of stories that respects knowledge from diverse sources, irrespective of culture, and ‘the way it is’. Danforth (1997) believes that it is through these narratives that many legitimate stories evolve, allowing individuals and groups to claim their voices, recognize their own identities, and create paths or action that don’t necessarily comply with traditional modernist/scientific truths. Often people who are placed in an area of marginalization, whether through their own body, or by association of their child, get trapped in a system of control and power that creates ‘docile bodies’. The only way out of this state, according to Foucault (1965) is through the reemergence of these politically
subdued voices and hopefully also through the meshing of scientific research and first hand perspectives of people with disabilities and their families (Danforth, 2000). What can be appreciated additionally about postmodernism is its ability to raise awareness about taken-for-granted beliefs about mental health and how they are saturated with western values. As a result, I believe many of the things we know about autism come from a perspective we have been taught to believe, no questions asked.

**Cross Cultural Dichotomies.** Culture influences how we conceptualize what is normal, abnormal, and suggests a solution. All cultures react to and define illness differently, and therefore no illness can exist outside of cultural boundaries. Autism as we know it in the west is not a cultural universal. Autism is manifested through similar symptoms, but is not understood the same everywhere. The medical model of disability, as previously discussed sees disability as a biological condition that automatically produces social misfortunes, and also a legitimate way of explaining and classifying a child’s difficulties (Ong-Dean, 2005). In addition, the medical model sees a person with a disability as someone who is physically limited due to issues of mobility, someone who is unable to communicate, someone who has a developmental or learning disability, or who is unable to perform daily living activities (LoBianco & Sheppard-Jones, 2007). The medical model is commonly used to diagnose and treat psychological disorders among people within the west. Autism is seen as a pathological problem, something that is wrong within the individual and therefore something that also must be fixed. A problem arises when the medical model neglects cultural factors that can undoubtedly affect a child’s development, both within western society and in other parts of the world. This representation leaves no room for flexibility, in both conceptualization and treatment of
autism. Within western society, there is an overt but also covert message that anything outside of normality is not an option. This is incredibly obvious when we consider the time spent on therapies for children with autism. If parents choose to not treat their child, they would be considered neglectful and abusive parents. In some ways, many treatments being used today could be considered abusive, but rarely do people in the norm consider this possibility.

Prominent literature discusses intensive behavioural, cognitive and language therapies. Rarely, do these treatments take into consideration culture, and often reinforce institutions of knowledge that structure the way we understand physical and psychological health and the duality between the body and the mind. These beliefs can be saturated within culturally specific assumptions (Parker, Georgaca, McLaughlin, & Stowell-Smith, 2005). These are the treatments we value, and therefore, these are the treatments that should be used and valued irrespective of culture.

Separating culture and human behaviour seems impractical because culture is embedded within our norms, rituals, and behaviours. It goes without saying that seeing autism as a problem in need of treatment is culturally bound. Grinker points out that, “The culture of science makes us believe that medicine and psychology can tell us truths about our bodies, when in fact they can only tell us about the particular set of phenomenon we’re looking at, or more precisely, about what time and culture tell us is meaningful to look at” (2007, p.130).

This also raises the issue of universality. According to Dumas and Nilsen (2003) autism is a universal phenomenon because the disorder has been described in similar ways in several different countries. Although definitions may be similar, discrepancies in
the literature regarding treatment were evident. Dumas and Nilsen (2003) state that, “few, if any social, cultural, or ethnic differences in epidemiology and characteristics of autism exist” (p.98). Although developed countries seem to have similar definitions, this is certainly not the case all over the world. In western society we tend to pathologize autism as a problem, a deviation from normal, and therefore something that needs to be fixed. Upon a diagnosis of autism parents are often encouraged to place their children in traditional intensive therapies for up to 40 hours a week. The focus tends to be on traditional therapies, one that reap a high “cure” rate.

Globally, there are many conceptualizations and therapies occurring. Despite what popular literature tells us, there is still not agreement about exactly what autism is and how it should be treated (Grinker, 2007). Many societies still do not even have a word for autism, and in others the symptoms of autism are not seen as abnormal, but rather divine or spiritual (Grinker, 2007). Given that culture is not a universal phenomenon, autism is also not universal. Beliefs about what autism is and how it should are diverse, and therefore these ideas are not applicable to everyone, nor should they be. It is interesting that dominant western ideals try to fit a disorder so complex and unique into the same standards across the world.

Case studies of families in Israel, China and Africa can highlight a very different picture of autism. The Jewish ultraorthodox community in Israel is known for their adherence to Jewish religious law, and their attempt to follow historical socio-cultural patterns. Most people in the Jewish ultraorthodox community want to protect themselves and their children from the effects of modernization (Shaked & Bilu, 2006). Health care is one area where the community chooses to remains dependent on practitioners situated
outside the community (Shaked & Bilu, 2006). From their perspective seeking health care crosses boundaries into non-religious sectors.

Studying thirty-two ultraorthodox Jewish families with children suspected of autism, Shaked and Bilu (2006) found that mothers did deviate from their religious views when searching for care for their children. Mothers believed that searching out typical medical care was the only way to find out if their child had a ‘real’ illness. Interestingly, they structured their language in a way that physicians would respond too, knowing that the physician would not have an understanding of their culture and religion. For example, even though mothers might have believed that their child was possessed by a spirit, they would not tell this to the physician. In addition, although many of the mothers in this study contacted medical doctors, they often took the advice of the spiritual leader when the two opinions clashed. When the advice of modern medicine was accepted, this advice was not taken without reservations.

Children diagnosed with autism used a variety of modern medical and educational treatments, as well as spiritual and mystical interventions. For example, “prayers and blessings from rabbis, lead treatment, traditional dream analysis, recitations of religious texts, holy water (drank by the child), amulets, changing the child’s name, exorcism, and prayer on the graves of revered rabbis in Israel of (sic) abroad” were used (Shaked & Bilu, 2006, p.7). Western culture might view these treatments as bizarre, unreasonable and without validity however, the Jewish ultra orthodox community felt that they added to the treatment options available, and enriched the supports available to their child.

Shaked and Bilu (2006) also asked mothers about why they thought their child was autistic. Both naturalistic and psychological factors were discussed. For example,
mothers spoke of labor complications and infections during pregnancy but also parental neglect, teasing from other children and emotional distress during pregnancy. Mothers also spoke of spiritual vulnerability, believing that God had targeted their children to, “contract autism” (Shaked & Bilu, 2006, p.12). In addition, mother’s used phrases such as, “It is from above” or “It was intended” (Shaked & Bilu, 2006, p.12). Two thirds of the mothers discussed the notion of the transmission of souls, the Jewish belief in reincarnation. Both levels of conceptualization were necessary for an understanding of autism, as although mothers understood the biological etiology of autism, they made a distinct separation between the child’s damaged brain and soul. Mothers also believed that because the child had a damaged brain, their spiritual sense was essentially high. The Jewish ultraorthodox community also had a certain acceptance about autism because they believed suffering was an opportunity for moral and spiritual growth (Shaked & Bilu, 2006).

In China, parents often become the only teacher for a child with autism. Chinese parents face many difficulties due to the social and cultural beliefs about disability (McCabe, 2007). Even parents themselves feel shame, because disabilities are seen as something the parents have done wrong. Children with autism are often rejected from the mainstream school system because teachers and administrators do not understand autism. Many parents chose not to send their children to school out of embarrassment, yet they still try to support their children the best they can. Mothers or the maternal side of the family are often blamed for a child having a disability.

Traditional Chinese beliefs about disability believe that persons with disabilities are, “useless burdens on society” (McCabe, 2007, p.40). Slowly, more people are starting
to understand that people with disabilities should have the right to a high quality of life. McCabe (2007) looked at 43 families who had children with autism. McCabe’s results indicate that parents believe practices and attitudes towards people with disabilities are discriminatory, due to low awareness and a lack of acceptance. Parents feared their children being singled out from other children because they were abnormal. This often made it difficult for parents to seek help. Chinese traditions such as obeying the father made mothers hesitant to tell people their child had autism, as they would obviously not be able to obey the father, and therefore were seen as having no future. Some parents did not use the word autism and instead said their child had a language delay. The Chinese translation for autism means “lonely disease,” which parents often found too hard to explain to people who had no conception of autism.

McCabe (2007) notes the importance of cultural factors. In China social conformity, as well as the child’s future potential are stressed, making it particularly difficult for parents to tell people their child has autism. Despite this, parents in China were resilient in seeking out help for their children wherever possible. The director of the Autism Institute in China claims that, “It is only parents in China who truly understand how essential parent involvement is” (McCabe, 2007, p.48). It is parents in China who routinely must give up their job, life activities, friends, and future success to actively care for their child.

Clark and Zhou (2005) found that Chinese treatments for autism use a mix of old and new therapies. Traditional Chinese medicine views autism as an imbalance in energy. Autism is a “Yin” disorder manifested by social isolation, lack of communication and apathy (Clark & Zhou, 2005). Yin disorders are treated through methods designed to
alleviate phlegm, which is considered the problem. Herbal and nutritional remedies are
suggested to reduce phlegm, while acupuncture is used to reduce disrupted neural
pathways in the brain. The exact areas of neurological dysfunction are targeted. Other
treatments in China include sensory integration therapies and relaxation techniques.
Applied behavioural analysis is used only in rare instances, and was rarely described in
the literature (Clark & Zhou, 2005).

In Africa, children are often not diagnosed with autism until age 6. The entire
family goes to the doctor with the child, because they believe the problem is within the
entire family (Grinker, 2007). In urban South Korea, psychiatrists diagnose children with
Reactive Attachment Disorder (RAD) a mental illness often linked to child neglect, but
more culturally acceptable than autism. In rural South Korea, autism is a more common
diagnosis, and children with autism are often known to the entire community. In contrast,
in Seoul children with autism are hidden from neighbours and rarely seen by relatives
(Grinker, 2007).

Navajo families treat disabled children with great compassion. Children with
disabilities are often not treated until the age of 6. Only then does the mother start to
shape and discipline the child. Children with disabilities are seen as becoming and
therefore minimal demands should be placed upon them. Autism is believed to be a result
of spiritual disharmony and Navajo people often have rituals to restore order. A
“Blessingway” is designed to ensure beauty, harmony and health within the spirit world.
Most Navajo people do not send their children to institutions because inside an institution
they would lose their ability to become true Navajo’s, leaving behind language and
culture (Grinker, 2007). Culture cannot possibly be separated from our beliefs about
disability. Ideas and beliefs are informed by and in cultures, and therefore cultures are an expression of the world in which we live. Cultural factors play a major role in determining how people understand and treat autism, given that culture is intertwined with our thoughts and behaviours. Alternative conceptualizations can only help to better inform clinicians, doctors, parents, and families around the globe, and to show that autism is not a static, one dimensional disorder but rather a unique, variable, entity that doesn't necessarily need to be 'normalized'.
Methodology

Phenomenology as a Means to Uncover Lived Experience

Human science research involves descriptive, interpretative approaches, self-reflection and/or critical analysis. Phenomenology describes how people orient themselves to lived experience (van Manen, 1990). From a phenomenological perspective to do research is always to question the way we experience the world, and to want to know the world in which we live (van Manen, 1990). Working with children with disabilities and their families has always been my passion. I am sincerely interested, and at times perplexed and concerned. It was only natural that I turned to phenomenological research. I wanted to know more, I needed to know more, and I wanted to hear it from the source. In some schools of research you’re taught not to get close to your participants, and yet you listen to some of their most intimate stories, and have the responsibility to portray them honestly, and do them justice as much as words can do. Connolly, Parsons, Craig and Posavad (2009, p.) affirm this notion, “We must do this without romanticizing a peaceful co-existence and without succumbing to a rationalized disparaging of irreconcilable difference or abject pity. And we must do this without imposing ourselves onto our analysis”.

In phenomenological research the questions asked are normally quite broad, given that the researcher does not want to influence the results of the study, or create a direction for the participants to follow. According to Moran and Mooney,

“Phenomenology means literally the science of phenomena, the science which studies appearance, and specifically the structure of appearing-the how of appearing-giving the phenomena or manifest appearances their due, remaining
loyal to the modes of appearance of things in the world, whether they belong to the physical, mathematical, cultural, aesthetic, religious or other domains. The phenomena of phenomenology are to be understood in a deliberately broad sense as including all forms of appearing, showing, manifesting, making evident or ‘evidencing’, bearing witness, truth-claiming, checking and verifying, including all forms of seeming, dissembling, occluding, obscuring, denying, and falsifying” (2002, p.5).

Phenomenological research seeks to understand the meaning of a lived experience from the perspective of the participant (Jackson, 2003). Lived experiences are defined as, “the everyday human experiences that are real to the individuals who experience them” (Jackson, 2003, p.161). Given that we are always reflecting back on an experience, phenomenology is not introspective but retrospective (van Manen, 1990). Phenomenology seeks to unravel the very nature of a phenomenon – what makes it some ‘thing’.

Phenomenology attempts to gain a deep understanding of the participants under study through thorough and careful examination. This detailed process is a rationale for choosing such a small sample. According to Jackson (2003) the purpose of a phenomenological study is to describe the essences of elements relating to “real” life. It is the phenomenologist’s role to expose and convey the meaning within the words of the participant. Phenomenology attempts to contribute to deeper understanding of lived experience by revealing taken-for-granted assumptions about these ways of knowing (Starks and Trinidad, 2007). A careful thoughtfulness, an attunement must be utilized to
interpret lived experience narratives to a certain degree of depth and richness (van Manen, 1990).

Phenomenology can also be focused around the idea of social action. Each person’s experience, views, and opinions are valued and meaningful, and are a way to create social change (Jackson, 2003). Given that the participants in this study are a marginalized group, the goal is that their words, when brought together will provide a picture for where social action can start. Parents, when informed, will be able to educate each other, and organizations about what they feel they need, not what other people tell them they need. As a researcher, my role is to enter into the experience with the participant, being an active listener, and communicator. By doing so, I will emerge as an instrument for data collection, because it is only when the researcher listens and understands the meaning of the participants words that the lived experience is revealed (Jackson, 2003). My goal is to create an animated, honest description of human actions, behaviours, intentions and experiences as they are lived within the participant’s life world.

The process of understanding and deconstructing the experience of parenting a child with autism will not come without challenges. It is a complex relationship, one that cannot be minimized or analyzed too harshly as it faces the reality of being constructed with a particular set of political, economical, and social time. Phenomenology as a qualitative technique allows the researcher to purposely seek information about a particular subject to uncover the way things appear to be in our experience (van Manen, 1990). Within this technique participants are considered co-informants, working with the researcher to produce meaning about the “child with autism”.

As a researcher, I have attempted not to presuppose my data by not constructing,“a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project”, however, that is not to say that phenomenology does not have methods (van Manen, 1990, p.29). Phenomenology does follow certain paths, but they are often discovered as a result of the response to the question at hand. Within this research study, I have based my knowledge in lived experience descriptions, while honoring the participant’s accounts of their lived experience, a methodology which serves both Giorgi’s descriptive approach (1986) and van Manen’s (1990) hermeneutic approach.

Phenomenology offers descriptions of experienced space, time, body and human relation as we live them (van Manen, 1996). Given that phenomenology is the study of essences, the researcher is interested in what the eidetic structure is or realized being of a particular phenomenon (van Manen, 1996). In this study, the researcher is trying to uncover what mother’s experience of parenting a child with autism is like. Given that descriptions are being analyzed from a variety of sources, the ideas will most definitely spread across various domains. The essence of being a parent or mother and having a child with autism in your life comes with complex and diverse meanings. It includes the way in which we come to know something; its properties and qualities. More so, the way a person defines or explains her experience. As a result, every piece of writing, or spoken word can be reduced, analyzed, and produce meaning. Essence is therefore, “a relational term that refers to the intentionalities of our world, to possible ways of encountering and relating to the things of our world before and while we understand or think them in language and poetic and conceptual thought” (van Manen, 1990, p.35).
Textual expression will take the form of journals and a focus group which will assist me in analyzing the lived experience. A number of themes will be used to give control and order to the research. Themes can assist the researcher in making sense of data and capturing particularly significant pieces of information. van Manen (1990) notes four existentials that are helpful guides for reflection: (a) lived space: spatiality (b) lived body: corporeality (c) lived time (temporality) and (d) lived human relation (relationality or communality). These categories ground human experience.

Lived space is the space we find ourselves in. It influences our self and the ways we experience our day to day existence. Lived body is our physical presence in the world. In this state we both reveal something about ourselves but also conceal something at the same time. We are not necessarily consciously aware of this ability. For example, when the body is the object of someone else’s gaze, it may lose its ability to act naturally (van Manen, 1990). Lived time is subjective time, or the temporal way of being in the world. Last, lived other is the lived relation we create and sustain with others in the interpersonal space we share with them.

The phenomenological approach supposes that the researcher must be sensitive – sensitive to the subtle undertones of language. "An authentic speaker must be a true listener, able to attune to the deep tonalities of language that normally fall out of our accustomed range of hearing" (van Manen, 1990, p.111). To do justice to the experience writing may turn into a complex process of re-writing (re-thinking, re-reflecting, re-cognizing). The re-writing creates depth, and a substantial and detailed understanding of the data. Giorgi (1986) proposes a particular sequence that guides the researcher’s process. The following describes Giorgi’s path to reduction.
(a) reading to get a sense of the whole

(b) separating the narrative into more complex ideas or phrases (into specific meaning units)

(c) rearticulating the participant’s words into more inquiry based language that is focused towards the nature of the question

(d) transforming the informants’ descriptions so that they are specific to their experience, but still maintain their connection and relevance to the research question
Procedure

Recruitment Method

Due to an existing relationship with the Autism Spectrum Disorders Summer Movement Program run through Brock University, I approached the Director of this program Maureen Connolly about the possibility of conducting this research. Given that I had also acted as a supervisor for this program attaining access to participants was readily accessible. From previous experience, I also knew that this population of parents would provide a rather diverse sample as their children were diagnosed with varying degrees of autism, many also with other co-morbid conditions. After gaining the Director’s consent to conduct this project I provided her with my contact information as well as an information and consent letter (Appendix A, Appendix B) which was then passed on to parents whose children attended the camp. Interested parents then had the opportunity to contact me if they were interested in participating or could verbally state their interest to the Director, at which time I would contact them through the information provided through the Director. The initial telephone conversation will be guided through a script (Appendix C).

Participants

The criteria used to determine the participants within this study included:

(a) Participants must be female

(b) Participants must be the mother of a child(ren) or adolescent(s) with autism

In addition, the child or adolescent can be any age with varying degrees of autism spectrum disorder. This may also include children with Asperger’s Syndrome, as well as children who have additional co-morbid conditions. In total, four mothers of children
with autism and one mother of a child with Asperger’s were invited to participate in this study. All five mothers choose to participate in the study. A sample size of five participants provides me with a small enough sample to conduct detailed analysis with but also provides some diversity among the participants. I am not attempting to determine common characteristics or generalize these findings to the larger population. Rather, I am striving to provide detailed lived experience accounts of what it is like to be the mother of a child with autism. Last, all five participants were Caucasian, with varying levels of socioeconomic status. All the mothers occupied the middle class; however, some were closer to upper middle class than others. All of these mothers reside in the Niagara Region. All of these mothers were strong advocates for their children, striving to gain new knowledge that would serve their child and the autism community. The mothers were all in similar yet quite different temporal positions of caring for their child. Some had children who were newly diagnosed, while others had adolescent children who had been diagnosed for some time.

Data Collection Method

Data were initially obtained through the use of journals. Participants were asked to complete the question: Describe the day to day experiences of living with a child with autism. This was completed through a paper and pencil task. I provided the mothers with both the journal and writing utensil. Over a one month period, mothers wrote about their experiences of living with a child with autism. Mothers were able to write as much or as little as they liked, and the topic was completely up to them. Although this is a rather unstructured method, I believed fewer guidelines would allow for a more open dialogue as mothers would not feel pressured to write about one thing in particular. Rather they
will write about whatever was most noticeable, poignant, difficult, or rewarding within their day. Given that I want to capture the every day experience without constraints and presupposing what mothers feel, this seems like a sufficient way to accomplish this.

Journaling is typically an under-utilized method in research; however, I believed this technique would work particularly well for this study, given the personal and sometimes sensitive nature of the topic (Berg, 2004). Mothers journaled at home in their own time, and therefore, did not have the presence of a researcher to influence their feelings. Journaling is a personal affair, one which allows the participant to reveal as much or as little as she liked. Upon completion, each participant submitted four descriptions, one per week for a month.

In addition, participants were asked to participate in a focus group that follows up on the information collected from their journal descriptions. Prior to the focus group a content level analysis/first reduction was conducted using specific and general descriptions as articulated by Giorgi (1985) as well as existential themes as articulated by van Manen (1906). I used the information collected from this initial analysis to guide the focus group. Focus groups often work well for small groups, and can be guided or unguided. For the purpose of this study, I used a number of questions to begin discussion; however, the majority of the focus group was rather unguided with participants choosing the most important topics for them to discuss. According to Berg (2004) when focus groups are used properly, they are extremely dynamic, as the comments of one participant often stimulate the comments of another. Furthermore, “a far larger number of ideas, issues, topics, and even solutions to a problem can be generated through group discussion than through individual conversations” (Berg, 2004, p.124). Given that all my
participants probably have more in common than not, this style of data collection is extremely beneficial.

Data Analysis

Each mother was provided with a self addressed envelope, and on completion of journaling was asked to mail back their journal submissions to me. Although this process worked well, it meant that journal submissions were arriving rather sporadically, and therefore my initial analysis occurred on a case by case basis. Once all the journals had been received, I did complete a full read of all the journals to recognize the noticeable similarities and differences.

A diamond analysis strategy was utilized to give structure to the journal analysis process. Although all the journals were analyzed for the components of body, space, time, relation, strong words and phrases, as well as a poetic re-cast, I included two of four journals from each participant when writing specific and general descriptions. Therefore, two of four journals used a descriptive or full array approach, while the remaining two journals used a narrative approach. For a visual of this technique please refer to Figure A.

After both the descriptive and narrative components were completed eidetic features of each were evident. These were cross checked with one another providing internal consistency. As a result, final eidetic features are evident that arise in both the descriptive and narrative pieces.

After transcription the focus group was read for strong words and phrases, body, space, time and relation. These findings were compared and contrasted with those from the journals. As a result, the constant comparative method was utilized. Both of these
components helped in understanding maternal stress, and more importantly what it means to be a mother of a child with autism.
Findings

Throughout the following section descriptive and narrative pieces, poetic re-casts, lifeworld existentials and eidetics found within the descriptive approach, narrative approach, and focus group will be examined. The descriptive approach presents both general descriptions and poetic re-casts for each participant, as well as a consolidating summary. Next, lifeworld existentials of body, space, time and relation from both descriptive and narrative approaches are explored. Following each existential are quotes from each participant that best highlight the eidetics found within each table. Following this section, is a table that describes strong words and phrases that were evident throughout the participant’s journals. Focus group existentials, quotes, and a consolidating summary follow. These are then followed by the narrative approach which presents poetic re-casts as well as a summary of the findings. Finally, a consolidation of the diamond analysis strategy first discussed in the analysis section which brings together each of the findings discussed previously.

Descriptive Approach: General Descriptions and Poetic Re-casts

Participant A:

General Description One. Each morning, she the mother anticipates what the day will bring – face punching, head banging, throwing objects, obsessive compulsive behaviours. Stress encompasses her thoughts as she wonders if the bus driver will wait or is a meltdown in her midst? Typical children would understand why the bus leaves – autistic children do not. Some days the mornings are calm, almost like she has a normal son. These moments are fleeting but the most enjoyable. Her life involves unpredictability and attunement to what could be, might be, probably will be. Be ready,
be prepared. She breathes a sigh of relief, and mutters many thank yous as the bus doors close and the bus pulls away. She returns to her normal life and awaits her abnormal delivery.

*Poetic Re-cast One.* Time dictates her ability to be normal. Aggression, stress, unpredictability and constant preparedness cast a shadow on many of her days. School buses symbolize happy children, eager learners and friendship. Mothers of children with autism see a chance at freedom – if only the bus door would close calmly, quietly, and quickly with little evidence of the mornings happenings she could be normal.

*General Description Two.* You can set your watch to the emergence of the wild child but it won’t help you understand why he emerges. At the snap of my fingers my cute, sweet, and calm child disappears and I am left with an out of control wild child. No adult can humanly match his speed. It all becomes a blur – the fridge door swings open, a dent in the hood fan, freezer dismantled, light bulbs smashing, knives cutting the wood counter. Gym memberships are unnecessary when you get this kind of workout every night. The wild child laughs hysterically – not amused I signal it’s bath time, gasp for a breath of air, regain my focus and calm my frazzled nerves only to realize my life has become a scene from the Wizard of Oz.

*Poetic Re-cast Two.* The watcher must be prepared – ready to lunge at the sign of danger. The wild child sits quietly planning his next move. With superhuman speed, the watcher has no chance. Possessions are destroyed, horrifying scenes come to life. The watcher is helpless gasping for breath. This is not how the scene is supposed to play out.
Participant B:

*General Description One.* Good weeks reflect appropriate carpet sitting, trips to McDonalds and relaxed mealtimes. Daily struggles with diet and assessments with psychologists create fear in present and future. A mother avoids the phone in fear of what the ‘professionals’ will tell her. Loss of control seems obvious out of sadness for what her child is and might never become. Pressure to ‘help’ her child creates feelings of frustration and disappointment and makes her wonder if all he will remember from his childhood is hear yelling at him.

*Poetic Re-cast One.* Mothers are supposed to be protectors but I can’t protect my child from this. I can ignore the phone calls but I know they’ll keep calling. The ‘professionals’ know what’s right, don’t they? They wouldn’t steer me down the wrong path, would they? Who I am without them, without him? Do they see my sweet, smart, affectionate son or do they see a body in need of taming? I listen to their results, I follow their rules hoping to help my son, and not erase the child I once knew.

*General Description Two.* A mother describes the reality of assessments. She knows that her child’s brain is wired differently – ASD and ADHD. Now she must explain this to the school, daycare and the doctor. She is caught off guard when her son questions what ADHD is. She explains that his brain is wired differently. He asks if this is why he is hyper and distracted. Sadness overcomes her as she realizes the struggles ahead. Asperger’s has changed her life. She is trying to accept her son’s differences and help him find a place in the world while struggling to find her own. Asperger’s doesn’t just affect the child but the mother’s sense of self as well. ASD is not a personal struggle – it’s a family one, but she will not let this beat her family.
Poetic Re-cast Two. There are aliens all around us. They live on foreign land with rules that are hard for them to understand. Some people fight for them to stay and beg them not to board that ship while others push them on their way. Battle lines are drawn, but we will just fight harder for them to stay.

Participant C:

General Description One. A mother feels her child’s frustration. She tries to understand, to figure out what he needs. She doesn’t and a figurine collides with a mirror in her daughter’s room. Maybe he understands what he did wrong – probably not. It doesn’t matter. It’s another mess to clean, another path of destruction to follow. She explains to her daughters that their brother can’t communicate with words his frustration, but this doesn’t fix their possessions being broken over and over again.

Poetic Re-cast One. I am a mother. I am an advocator. I am a cleaner. I am an explainer. I am a teacher. I am a supporter. I am a modifier. I am an understander. I am exhausted.

Poetic Re-cast One B. There is only 24 hours in a day. I need more. Challenge, destruction, and explanation take up the first 24 – what is left for me? I am exhausted, frustrated, and needing my own space. Do they have respite care for parents?

General Description Two. A mother wonders if a break for her is really a break at all. Vacations make it hard to adjust to physical aggression. She tries not to take it personally and attempts to keep a thick skin. It is personal though. Your own flesh and blood hits you and you can’t understand why – you can’t reason with him – you can’t explain why that’s not okay.
Dinner time brings another hard shove and the administration of evening medications.

A support worker comes for a much needed break. The funding is dwindling and she considers the months left that respite care is needed.

*Poetic Re-cast Two.* Break – the time away from another, the disconnect between two entities, the necessary space created, the chance at a normal family.

*Participant D:*

*General Description One.* A woman fears having a handicapped child. She wonders how those parents cope until she becomes the mother of a child with autism. She does her best and tries to enjoy the few normal parts of her day. She feels the pressure of having this child, knowing their watching, judging. She jokes but her pain is evident. She worries for her other children when her own patience runs low. Days are spent guarding their feelings, setting up calm spaces and making everyone happy. When he sleeps, he is calm but she worries for what the future will bring.

*Poetic Re-cast One.* I am a buffer. Buffer between my child and the school. Buffer between my child and other children. Buffer between my child and his siblings. Buffer between my child and my family. Buffer between my child and the stares and comments. Buffer between my child and the therapists. I buffer the aspects of the world that collide with my child, but who will be my buffer?

*General Description Two.* It takes months to recover from Christmas break. March Break is approaching and the schedule is filled with activities that hopefully aren’t too overwhelming. The school thinks --- is more reasonable on more medication but they also think he is too loud. These choices are hard to make. How will they influence his
little body long term? He’s four – I have time. My other children need me too. --- gets so much attention and effort. My husband and I are taking a vacation with our 6 year old our other children will stay at home. It’s hard to know how this change will affect him. I worry.

Poetic Re-cast Two. I am a crisis intervention worker within my own home. I attempt to manage or minimize change, disruption and chaos. I am always attempting to be one step ahead – thinking, planning, preparing. I must always be alert, watching and waiting.

Participant E:

General Description One. A mother grasps at brief moments of one on one interaction. She notices the small, but poignant moments like this because they don’t happen often enough. Her child is happy. Her world stops as she watches, captivated by him. This is what life is all about – feeling the joy and happiness your child feels.

Poetic Re-cast One. Not all mothers have to appreciate eye contact.

But I do.

Not all mothers have to wait patiently to interact with their child.

But I do.

Not all mothers put their world on hold to dance, to laugh, to roll around the TV room floor.

But I do.

Not all mothers feel this moment may never happen again.

But I do.
**General Description Two.** Drained, she cleans up the pee on the bathroom floor where he teenage son missed the toilet. She changes him, cleans the bathroom floor, and starts a load of laundry. She wishes she has more help. If she could just clone herself. There’s never enough time in the day to get everything done, enjoy her children, and have ‘me’ time. She is not worried about herself though. She is selfless, and thinks about what extra time in the day could do for her son. If only there was more time.

*Poetic Re-cast Two.* Her life is enveloped in his. His successes are hers. His failures are hers. One persons life wrapped up in another – their very being evident in the eyes of their child.

**General Description Three.** Repetitive incidences, hours, days, weeks and months have become her life. Nothing is ever done once. Her child wants to run around naked but her other children have friends over. She worries about the embarrassment they must feel. She takes the time to give him some sensory input, brushing him and putting on a heavy sweater.

She worries for --- siblings. How must they deal with a brother like him? How will this affect them as individuals? One more thing she cannot control or predict.

*Poetic Re-cast Three.* I call him to play, but he doesn’t come.

I look him in the eye, but he doesn’t look back.

I show him the way, but he doesn’t follow.

I ask him a question, but he doesn’t answer.

We are brothers without words.
GENERAL DESCRIPTION FOUR. Being a parent of a child with autism means you’re part of a special social circle. You didn’t choose this group – no parent would, but you are here nonetheless. Family and friends don’t understand the choices we make. It’s hard to explain out life to them when theirs is so drastically different. The guilt sets in early and lingers during the day. Outings become a time to explain ourselves rather than enjoy ourselves. Help offered is often more stressful than helpful.

POETIC RE-CAST FOUR A. Listen to what I’m saying without saying anything at all. Watch quietly, without intruding or analyzing. Show empathy without showing pity.

POETIC RE-CAST FOUR B. He wasn’t with us. It was too hard to explain. We are anxious, contemplating our decision, waiting to be questioned. He is at home. ‘Friends’ ask why, nodding politely at our answers but not really listening to what our bodies are telling them. I wish people would listen, be genuinely concerned. Listen, just listen.

CONSOLIDATING SUMMARY

Mothers of children with autism often live a complicated existence. They must anticipate their child’s every move, but have a child whose behaviour is anything but predictable. These moments demand calmness, clarity, focus and attunement. They must be thinking, planning and doing. In many situations they must be superhuman, combining every characteristic they possess to watch and protect their child. Most days, as one situation ends another quickly begins, so mothers are constantly regaining both their patience and their energy.

This is not to diminish what parents of typical children face, as I would argue that they too face similar situations that demand these characteristics. The difference is, mothers of children with autism are always in this state of ‘flight or fight’, with no
chance of ‘flight’ and worry about their children jumping head first out of windows not deciding to colour their hair blue.

All of these mothers have expressed that their lives aren’t normal, and all of them still seem to be striving for some piece of normality to hold onto. In some cases, it is ignoring the ‘professionals’ who want to be a part of your life, but you don’t want to be a part of theirs. In others, it is the moment where your 17 year old expresses emotions for the first time or when your child wants to help you cook. Typical parents may not appreciate or be as aware of simple, mundane everyday things that they expect their child will do, but parents of children with autism have to hold onto these bits of ‘normalcy’ with intensity because they know how quickly they may be gone.

It becomes evident quickly that all of these mothers have lost bits of themselves. Sometimes, it is the simple ability to be able to sit alone and think, others the friends that stop calling or coming by because they just don’t get your life. Over time, the role they maintain as mothers influences their role in other parts of life. Acting as a buffer for their child, bouncing back and forth to preserve other people’s happiness diminishes the ability to do this for oneself.
**Table 1: Lived Body (Corporeality)**

<table>
<thead>
<tr>
<th></th>
<th>Descriptive</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>○ Peaks of intense stress, relief but very brief.</td>
<td>○ Must be patient.</td>
</tr>
<tr>
<td></td>
<td>○ Distinct separation between the person she is, the person she wants to be,</td>
<td>○ Must have energy.</td>
</tr>
<tr>
<td></td>
<td>and the person she can be when the child is not present.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Body is in a state of constant chaos.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Gasping for breath.</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>○ Shell shocked.</td>
<td>○ Keeps emotions in check.</td>
</tr>
<tr>
<td></td>
<td>○ Caught off guard.</td>
<td>○ Struggling.</td>
</tr>
<tr>
<td></td>
<td>○ Sadness.</td>
<td>○ Hated.</td>
</tr>
<tr>
<td></td>
<td>○ Struggle.</td>
<td>○ Tired.</td>
</tr>
<tr>
<td></td>
<td>○ Wants to please.</td>
<td>○ Wants to please.</td>
</tr>
<tr>
<td></td>
<td>○ Fear.</td>
<td>○ Fear.</td>
</tr>
<tr>
<td>C</td>
<td>○ Exhausted.</td>
<td>○ Always thinking.</td>
</tr>
<tr>
<td></td>
<td>○ Cleaner.</td>
<td>○ Worrying.</td>
</tr>
<tr>
<td></td>
<td>○ Physically injured.</td>
<td>○ Constant struggle.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>○ Attacked physically.</td>
</tr>
<tr>
<td>D</td>
<td>○ Head knows it’s not her fault, but her heart feels otherwise.</td>
<td>○ Struggle.</td>
</tr>
<tr>
<td></td>
<td>○ Drained.</td>
<td>○ Fighting.</td>
</tr>
<tr>
<td></td>
<td>○ Never can give enough.</td>
<td>○ Advocating.</td>
</tr>
<tr>
<td></td>
<td>○ Worry.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Constantly learning.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>○ Trying to laugh.</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>○ Drained.</td>
<td>○ Grieving loss of normality.</td>
</tr>
<tr>
<td></td>
<td>○ Wants to clone self.</td>
<td>○ Physically dressing him.</td>
</tr>
<tr>
<td></td>
<td>○ Misunderstood.</td>
<td>○ Constantly thinking.</td>
</tr>
<tr>
<td></td>
<td>○ Hardship</td>
<td>○ Wanting to cry.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>○ Excitement.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>○ Exhaustion.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>○ Frustration.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>○ Killing her.</td>
</tr>
</tbody>
</table>
Lived Body Quotations

1. “If the self abusive behaviours start right away you will need to dig deep down and pull out every ounce of patience and energy you have to get yourself through the day. Even then, you will need even more” (Participant A).

2. “He asked if it was why he brain worked so fast and why he gets distracted by everything. It was really sad for me. It is hard to watch him struggle” (Participant B).

3. “I get very tired of this. Sometimes I feel like that’s all I do. Walk behind him and clean up the path of destruction” (Participant C).

4. “He gave me a hard shove from behind, almost into the table. He makes me really made when he does that. I know he has all these frustrations and no way to express them, very frustrating on both sides” (Participant C).

5. “I am trying to learn to enjoy the successes and not feel so low when he has a challenging day. I know in my head that it is NOT MY FAULT, but it is hard to convince my heart and my neighbors. Ha! I also worry about the effects of his behaviour on my daughters. I feel so drained (so often), how must they feel”? (Participant D).

6. “Oh, I am so tired. I just want him to sleep through the night” (Participant E).
### Table 2: Lived Space (Spatiality)

<table>
<thead>
<tr>
<th></th>
<th>Descriptive</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>o When child is absent, she is able to return to ‘normal’ life.</td>
<td>o N/A</td>
</tr>
<tr>
<td>B</td>
<td>o Avoidance of the ‘professionals’ – attempt to create and maintain a distinct space between the professionals and her family. o Would rather change the world around them then her child.</td>
<td>o N/A</td>
</tr>
<tr>
<td>C</td>
<td>o Distinct calm down spaces – mother separate from this.</td>
<td>o The worker taking child out of the house makes everyone happy.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Spaces strewn with food bits – child wants to walk around the house while eating.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o If only there was a place to go where we didn’t have to worry about all the weird behaviours.</td>
</tr>
<tr>
<td>D</td>
<td>o Wants/needs space away from child.</td>
<td>o Constant discussions of boundaries.</td>
</tr>
<tr>
<td></td>
<td>o Creates space for siblings away from child.</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>o Bathroom floor peed on by teenage son.</td>
<td>o Unable to be in public space.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Unable to be in family space.</td>
</tr>
</tbody>
</table>

**Lived Space Quotations**

1. “I must say though, that I breathe a sigh of relief and mutter many words of thanks and gratitude when those bus doors close and the bus pulls away from the curb. I can now return to my normal life until my 3:30 delivery returns” (Participant A).

2. “He finished all his testing and they are ready to share their findings with my husband and myself. I, however, am not ready to hear what they have to say. I have actually been avoiding their phone calls” (Participant B).
3. "Fortunately, his worker is taking him out for a few hours. That makes everyone happy" (Participant C).

4. "He is very messy and quite happy to wander around while eating. I’m always finding bits of food lying on the ground, especially at the computer” (Participant C).

5. "It’s great to go someplace (or at least try) and not worry about weird behaviour” (Participant C).

6. “Even after much discussion of boundaries, neither one seemed to have learned the social cue” (Participant D).

7. “He went to the washroom but he wasn’t back far enough on the toilet and peed into his pants and all over the floor” (Participant E).
### Table 3: Lived Time (Temporality)

<table>
<thead>
<tr>
<th></th>
<th>Descriptive</th>
<th>Narrative</th>
</tr>
</thead>
</table>
| A | • Waiting for behaviour.  
    • Waiting for normalcy.  
    • Waiting for the bus to take him.  
    • Emergence of the wild child begins at a certain time every day.  
    • Behaviour monitored by time. | • Bus delivers wild child every day at a certain time.  
                                     • Enjoying time with child.  
                                     • Respite care gives mother a much needed break – and time for herself and other child. |
| B | • Importance of 15 minutes (carpet time).  
    • Flurry of meetings. | • N/A                                                                       |
| C | • Early Release Days extremely challenging – more time with child.  
    • Must fill the days with activities.  
    • Time of medication dictates daily behaviour. | • Agitation before bus when there is a time crunch.  
                                               • Thinking about how to bring him down fast.  
                                               • Three days weekends = more time, more challenge.  
                                               • Busy, busy all week. |
| D | • Needs a four day holiday – looking forward to uninterrupted time.  
    • Months to recover from a break in routine. | • Spends a lot of time teaching child the rules of the outside world. |
| E | • So much to do, and never enough time.  
    • More time = less rushing = more enjoyment.  
    • Dressing child 3 times in a matter of minutes. | • Don’t have time for that.  
                                               • Differences in milestones between children – starting to express emotion at 17 years old.  
                                               • Set watch to when child gets up in the night. |

**Lived Time Quotations**

1. “The emergence of the wild child begins around 6:00 pm almost every night”
   
   (Participant A).

2. “--- has been getting a lot of praise at school for being able to sit appropriately during carpet time (15 min). This seems like a simple task, but for --- it is a huge accomplishment” (Participant B).
3. “The assessment reports have all been sent out. Now begins a flurry of meetings: school, doctor, daycare. Let the fun begin” (Participant B).

4. “About 10 min before the bus he started getting agitated. Always a question of how to bring him down fast” (Participant C).

5. “We are spending a lot of time trying to teach --- the rules of the outside world” (Participant D).

6. “There just seems like there is so much to do, and not enough time to do it” (Participant E).
Table 4: Lived Other (Relationality)

<table>
<thead>
<tr>
<th></th>
<th>Descriptive</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>o Perfectly normal, calm days, almost like interacting with a ‘normal’ child but these moments are few and fleeting, but truly enjoyable.</td>
<td>o Wants to spend time with other son. o Wants to connect, relate and communicate with him.</td>
</tr>
<tr>
<td>B</td>
<td>o Child frustrated with mother. o Constant nagging – feels like she is heaping negativity on him. o Frustration = Snapping. o Worries for their long term relationship. Will he only remember me yelling at him? o Nothing without him.</td>
<td>o Hates me and wants to live somewhere else. o Shifting mood. o Madness seems inconsequential.</td>
</tr>
<tr>
<td>C</td>
<td>o Feels her child’s frustration. o Possessions of family constantly being broken. o Unable to communicate frustrations. o Happy to see him but is it worth going away – so hard to get into the routine of dealing with him again.</td>
<td>o Explaining to other people. No one else wants to take any responsibility. o Exciting to see him try to communicate. o Tense relationship. o Guilt. o Proud of little but big accomplishments.</td>
</tr>
<tr>
<td>D</td>
<td>o Loves to watch her sleeping child – sweet, calm. o --- is one of three children – relationship with all of them just as important. o Desires alone time with husband and daughter.</td>
<td>o Upset at other parents’ disgust with her child. o Always mother – dynamic of this relationship. o Helpful to have friends you can debrief with.</td>
</tr>
<tr>
<td>E</td>
<td>o Joy when she relates to him. o Captivated by his laughter. o Nothing else matters when he wants my attention. o This is what life is all about – feeling the joy and happiness your child is feeling.</td>
<td>o Frustrated with his behaviour. o Wonders who she can share her sons successes with.</td>
</tr>
</tbody>
</table>
Lived Other Quotations

1. “Not all days begin in this manner as there are some that can be perfectly normal and calm. Almost like having a normal child...these fleeting moments are truly enjoyable” (Participant A).

2. “He gets very frustrated with me for being on his case. I feel like I am constantly nagging him. Clean up, listen, pay attention, keep your voice down. I feel that I am heaping negativity on him. I just get to such a level of frustration that I “snap”. I hope that when he grows up he doesn’t just remember me yelling at him” (Participant B).

3. “Some nights are easy and some are a nightmare (no pun intended). He will scream at my husband and I, tell us that he hates us and wants to live somewhere else. After working all day it is hard to keep my emotions in check. i am tired and want to spend quality time with him. I try to please but sometimes my efforts go unrewarded. Then his mood will shift, I will get an apology and --- will lay his hand on my cheek and whisper, ‘until tomorrow my little angel’. After that all the madness seems so inconsequential” (Participant B).

4. “He even put his Dad’s picture on his communication book while we were out, I want Dad. It’s so exciting to see when he does things like that. It’s like a window opens and you get to sneak a peek at his feelings” (Participant C).

5. “I was helping him get his stuff and he hauled off and hit me in the head. As happy as I am to see him, I sometimes wonder if it’s worth going away at all. I find it very difficult to get back into the routine of dealing with him. I try not to
take it personally that he hits me but it’s really hard to keep a “thick skin” about it (Participant C).

6. “I find it so helpful to have a few special friends that I can debrief with, laugh with, and muddle through our roles as Moms with” (Participant D).

7. “It’s funny – he is starting to express emotion at the age of 17. But who do I share this with? Friends who have children that are 17 are dealing with that child getting ready to go to university and being a new driver” (Participant E).
<table>
<thead>
<tr>
<th></th>
<th>Descriptive</th>
<th>Narrative</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Fleeting.</td>
<td>Wild child.</td>
</tr>
<tr>
<td></td>
<td>Delivery.</td>
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<td></td>
<td>Blur.</td>
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<td></td>
<td>Watch.</td>
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</tr>
<tr>
<td>B</td>
<td>Reinforce.</td>
<td>Zombie.</td>
</tr>
<tr>
<td></td>
<td>Off guard.</td>
<td>Off the charts.</td>
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<tr>
<td></td>
<td>ADHD thing.</td>
<td>Nightmare.</td>
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<tr>
<td></td>
<td></td>
<td>Madness.</td>
</tr>
<tr>
<td>C</td>
<td>Path of destruction.</td>
<td>Touchy situation.</td>
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<td></td>
<td>Thick skin.</td>
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<td>D</td>
<td>Buffer.</td>
<td>Tolerate.</td>
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<td>Report.</td>
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<td></td>
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<td>Disgusted.</td>
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<td></td>
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<td>Outside world.</td>
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<tr>
<td>E</td>
<td>N/A</td>
<td>Disturbed.</td>
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<td></td>
<td></td>
<td>Battle.</td>
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### Table 6: Focus Group Existentials

<table>
<thead>
<tr>
<th>Lived Body</th>
<th>Focus Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Corporeality)</td>
<td>o Shameful.</td>
</tr>
<tr>
<td></td>
<td>o Explainer.</td>
</tr>
<tr>
<td></td>
<td>o Pressured.</td>
</tr>
<tr>
<td></td>
<td>o The bad guy.</td>
</tr>
<tr>
<td></td>
<td>o Irritated.</td>
</tr>
<tr>
<td></td>
<td>o Tired.</td>
</tr>
<tr>
<td></td>
<td>o Anxious</td>
</tr>
<tr>
<td></td>
<td>o Thankful.</td>
</tr>
<tr>
<td></td>
<td>o Worried.</td>
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<td></td>
<td>o Frightened.</td>
</tr>
<tr>
<td></td>
<td>o Always stressed – always on edge.</td>
</tr>
<tr>
<td></td>
<td>o Exhausted.</td>
</tr>
<tr>
<td></td>
<td>o Embarrassed.</td>
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<tr>
<td></td>
<td>o Adaptive.</td>
</tr>
<tr>
<td></td>
<td>o Waiting – watching for something awful to happen.</td>
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<table>
<thead>
<tr>
<th>Lived Space</th>
<th>Focus Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Spatiality)</td>
<td>o Messy – food everywhere.</td>
</tr>
<tr>
<td></td>
<td>o Every space is stressful when child is present.</td>
</tr>
<tr>
<td></td>
<td>o Create calm spaces for other children.</td>
</tr>
<tr>
<td></td>
<td>o Can’t be here, can’t be there – few acceptable, comfortable spaces.</td>
</tr>
<tr>
<td></td>
<td>o Stressful for siblings – protect themselves and their things.</td>
</tr>
<tr>
<td></td>
<td>o House is a warzone.</td>
</tr>
<tr>
<td></td>
<td>o Rooms are barren.</td>
</tr>
<tr>
<td></td>
<td>o Windows nailed shut.</td>
</tr>
<tr>
<td></td>
<td>o Toilet lids removed.</td>
</tr>
<tr>
<td></td>
<td>o Don’t go places that aren’t safe – grandma has 7 glass tables.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lived Time</th>
<th>Focus Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Temporality)</td>
<td>o Three times to teach another child, 1 million to teach my child.</td>
</tr>
<tr>
<td></td>
<td>o Time that everyday ‘little’ things take. They eventually turn into big things.</td>
</tr>
<tr>
<td></td>
<td>o Husband works extra hours to afford necessities.</td>
</tr>
<tr>
<td></td>
<td>o Influence of present time on other children.</td>
</tr>
<tr>
<td></td>
<td>o No time for self.</td>
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<tr>
<td></td>
<td>o Lagging behind with child – time keeps moving but your child doesn’t.</td>
</tr>
<tr>
<td></td>
<td>o Never know how much time you will get somewhere – how long before you make a scene?</td>
</tr>
<tr>
<td></td>
<td>o Shear lack of time.</td>
</tr>
<tr>
<td></td>
<td>o Always on guard, waiting.</td>
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</table>

<table>
<thead>
<tr>
<th>Lived Other</th>
<th>Focus Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Relationality)</td>
<td>o Deal with child 24 hours a day.</td>
</tr>
<tr>
<td></td>
<td>o Remind other children that just because he can’t talk doesn’t mean he can’t feel it.</td>
</tr>
<tr>
<td></td>
<td>o Thankful husband works at home for a break.</td>
</tr>
<tr>
<td></td>
<td>o Husband calming factor – good guy vs. bad guy.</td>
</tr>
<tr>
<td></td>
<td>o Takes out irritation on child.</td>
</tr>
</tbody>
</table>
Relations with new respite workers.
Feels people sometime hate her child.
Siblings motherly, until she can’t take it anymore.
Siblings frustrated, angry and hostile.
Understand that siblings will be responsible for their brother/sister when we’re not here anymore.

<table>
<thead>
<tr>
<th>Strong Words and Phrases</th>
<th>Enforcer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fresh.</td>
<td></td>
</tr>
<tr>
<td>Inconspicuous.</td>
<td></td>
</tr>
<tr>
<td>Their unpredictable. That’s how you plan your life.</td>
<td></td>
</tr>
<tr>
<td>Deal with it. This is the way it is. Nobody’s equal.</td>
<td></td>
</tr>
</tbody>
</table>

Focus Group Quotations

1. “Other people’s opinions? I feel a lot of shame. I feel a lot of eyes on me. I have had to just work past that and focus on my kids but umm, I feel there’s a lot of explaining to do. I just stopped explaining to grocery clerks who don’t need to know and just the core people. It’s a lot of pressure” (Participant D).

2. “And I will admit I am thankful he works at home because there are times when I say you have to help/come. He seems to be a calming factor on ---. And I can see that. Like, sometimes I am sure --- is frustrated with me. He’s the fun guy” (Participant C).

3. “He is really messy. Just food everywhere, on the floor and I am the one who has to clean it up so it would make sense that I would want him to learn how to eat properly at the table and that’s not such a sticking point for my husband cause he doesn’t clean up. So, you know, I am maybe like the stickler. They don’t seem like big things but they are when its everyday” (Participant C).

4. “My husband gets up at the crack of dawn and he is gone and so he is there for the fun times which is. I’m not knocking him because he brings in our income and it is getting better as my son progresses and develops so he is enjoying him a lot
more but I found that I am still in the routine of he is not able to dress himself fully yet, so umm getting pants on and shirts can’t them over his head, working on those things, the day in and day out, teaching him all these skills, umm like it is with any other kid buts its like if it takes you three times to teach another child it takes 100….1 million times to teach my son. And I think its cause we’re human, we get irritated and tired. I don’t want to say I take it out on him but I get irritated” (Participant D).

5. “I don’t expect anyone to be any certain way with him but I don’t feel like she wants to knock him into next week and I feel that a lot of times from people because he is so wild, like he’s a wild child, that I don’t want people to hate him and she adores him, and the things that he says she is amused by and she can’t wait to tell me. I feel safe and comfortable. We thought about respite care, but I really worry about him getting abused. He is very difficult “(Participant D).

6. “…she is very motherly of him unless she just can’t take it anymore. And then she just bubbles over and freaks out which is okay it needs to now and then but my 2 year old doesn’t get it at all, she is frustrated, she’s very angry but I’m curious to see how that’s going to go so we’re trying to put in place that she gets enough space and her own time so she’s not always frustrated. So, she doesn’t grow up angry and hostile” (Participant D).

7. “We make a point of not saying that you’re not responsible for your brother because they are. They don’t have to be his caregiver but I’m never going to say you’re not going to be responsible for him cause that’s not fair, because that’s not the truth” (Participant C).
8. “Yep, mine is almost 13 now and kind of like you said when things are a little rough you try and hide it at first when their younger – your reaction to what’s going on; especially the physical stuff. I don’t want them to see him hurt me like that but at some point you can’t avoid it” (Participant C).

9. “But ya, even at 11, I still have to supervise --- getting dressed, make sure he eats "body really. He still needs to be supervised so…on the one hand half the kids are doing what they’re supposed to be which is kind of normal but you’re still lagging back here with him” (Participant C).

10. “And it’s the small things, like I would love to just go to Happy Rolph’s and not have all those people there, like have Happy Rolph’s to myself and then he can be as peculiar, odd…” (Participant D).

11. “She’s never had any time away from him, and I didn’t know how much she’s enjoyed herself until I watched her feel that stress” (Participant D).

12. “I noticed that when my older son because when --- accomplishes something you’re like, ‘wow, look at that,’ I don’t know, he put his pants on or something, and --- is like, ‘oh wow,’ you know, I brushed my hair today” (Participant A).

13. “I want to live in the country because I can’t take it anymore. I want to look through the windows and not feel everyone’s saying, ‘ohh, there are those --- people again’ (Participant D).

14. “That’s like with my son --- because our houses are close together and this year as I was telling you how he’s been difficult this year because he’s in puberty. Well, he was getting up at night banging on his door and the walls and this would be going on all night. We were exhausted. This went on for about 3 months. I was
upping his meds during this period, and umm, so a few weeks. It was maybe three weeks later, my neighbour comes over and my husband was cleaning out the car. He goes, ‘is everything alright over there?’ They could actually hear the banding. They probably thought we were beating James or something. No, it’s just James. Oh my god. If they can hear it, it was probably keeping them up at night” (Participant A).

15. “He gets the cutlery out. And thank god I don’t have nice cupboards cause I’d be sick. He takes the drawer and he hits the back of the knives, so there is like all these dents in my drawers. Then he pushes the drawer through so you know you can’t close the drawer, so I’m trying to get this thing. Then he goes over to the fridge” (Participant A).

16. “I’m learning to live with holes in the wall” (Participant C).

17. “Oh, our house is. I said to my husband, you know one of these days like if he ever moves into a group home, like we have to sell this house, like we have to gut it. His bedroom has to be completely re-done because there are holes everywhere. Like when he was small he used to pick at the nail holes and then pick away at the drywall and then or either that or he’d hit his head and go through it and then he pulls the dry wall so we have like wooden boards all over his room where there are holes because why fix it? His room is disgusting. I hate it” (Participant A).

18. “We got rid of all the furniture except for the bed, cause he would tip everything over” (Participant D).
19. “Like, you’re always stressed, you’re always on edge, thinking okay when he’s at school or if, he’s not using respite, what’s he gonna do, what’s he gonna break or is he going to hurt someone? (Participant A).

20. “My mother has 7 glass top tables. And she won’t get rid of them. You know, so, we just don’t go there” (Participant D).

21. “We find we get up and get at it and attack the world early in the morning because the crowds aren’t there, and they know us at the grocery store now. You know what I mean like, it doesn’t take too long til people recognize us” (Participant D).

22. “But ah, I find my friends don’t want to hear it. They’ve stopped asking, and that’s okay” (Participant D).

23. “You know, if I can go somewhere once a week and just be and all my kids can just run around and --- can do whatever he needs to do – touch every sign as he leaves, and knowing that it’s okay and no one is judging you. That’s a feel good” (Participant D).

**Consolidating Summary**

The lifeworld existentials of body, space, time and relation have helped to illuminate the common eidetic features in the lives of mothers of children with autism. Most people can reflect on periods of intense stress; periods that were difficult to make it through. Mothers live with bodies that are in constant chaos and stress, and yet they must always have the energy to withstand whatever comes next with little or no resting period for themselves. Despite the fact that many of these mothers have been dealing with the constant upheaval for years most of them express that its not getting any easier, and instead getting harder as their child ages and gets closer to puberty. They still find their
child’s behaviour shocking, and find themselves grieving for the child that should have been.

Many of these mothers were being physically harmed by their child. This is a complex issue to deal with given that many of their children have no ability to verbalize or express their frustrations and instead push, shove, or hit their mothers. That being said, this physical aggression creates tension in a relationship that already has very little or no reciprocity. Of course, these mothers love their children and quite obviously would do anything for them, but it’s a complicated relationship when your child is unable to express the emotions that ground human connection.

It became evident that the space with and without the child is rather different. Without the child, mothers felt they had a chance at normalcy, if only for the day. Their houses were described as war zones – with bits of food strewn throughout the house, pee on the bathroom floors, broken possessions, windows nailed shut, toilet lids removed and barren bedrooms. Most mothers felt that there was no space where they could go other than their house where their child can just be, and they don’t have to worry about all the weird behaviour. As a result, the house becomes the only place where they can just be, however, it also becomes the place where destruction occurs.

There is never enough time in the day when you have a child with autism. Ironically, although mothers expressed wanting time for themselves, they also expressed that more time would allow them to better serve their child. It was also apparent that time had some very negative connotations. For example, mothers thought of the time they spend waiting for something bad to happen or the fact that they could never leave their child alone for any period of time because they’d never know what they’d come back to.
Issues of relation are perhaps the most poignant and raw. Mothers expressed issues of connection, and communication and how it was unlikely for many of them that this would happen. Calm, normal, enjoyable moments were few and fleeting. These mothers worry about if what they are doing is right. They worry about their child hating them when they are older for constantly nagging them. They worry about explaining to others. They worry about others watching them. They feel shame – for their child and for themselves. They feel alone and wonder who they can share their child’s successes with as they are so drastically different from parents of typical children. With that said, they also are more apt to notice and appreciate the moments of connection that do occur or when someone understands and appreciates their child without judging them or feeling pity for them.
Narrative Approach: Poetic Re-casts

Participant A:

_Poetic Re-cast Three._ Uncertainty and unpredictability can make it hard to appreciate life’s blessings. Moments of down time and calmness seem fewer and far between and the life that was planned for and dreamed of a distant memory. Despite this, mothers of children with autism find enjoyment in different and unique spaces – ones that typical parents of typical children may never have to grasp at but that parents of children with autism hold onto with ferocity.

_Poetic Re-cast Four._ Break – the time away from another, the disconnect between two entities, the necessary space created, the chance at a normal family.

Participant B:

_Poetic Re-cast Three._

Madness and sanity.

Hate and love.

Social and recluse.

Devil and angel.

Positive and negative.

Clarity and confusion.

Distinctly different, yet closely related.

_Poetic Re-cast Four._ Medicated zombies sit quietly, behave and don’t create a scene. Is this a more acceptable alternative than having a child with autism? Are ASD’s not an acceptable way of being? How do we determine what success is?

Participant C:
Poetic Re-cast Three. In my world, time ticks by but my child doesn’t change. My window of freedom gets smaller. I am an ‘always’ mother bonded to my child forever and battling the uninformed and uncooperative.

Poetic Re-cast Four. Every day I open the window hoping the little boy looking through will come inside. Harsh winds, and cold nights force the window closed but each morning I open it again hoping for a glimpse of the boy I once knew.

Poetic Re-cast Five. He should understand that it’s too cold to ride his bike. He should be able to tell me why he’s frustrated. He should eat food from all four food groups. He should sit at the dinner table. He should.

Poetic Re-cast Six.

Most kids vs. my kid.

Most kids don’t attack their parents.

Most kids can play a whole game of bowling without falling apart.

Most kids look forward to the movie theatre.

Most kids have parents who enjoy March Break.

My kid isn’t most kids.

Participant D:

Poetic Re-cast Three A.

An outside world, an inside child.

‘Bad behaviour’, ‘Normal child.’

‘Bad mother’, Disgusted looks.

An inside family.
Poetic Re-cast Three B. I must always keep a watchful eye because I know they are watching me. They’re part of a different world – a calmer, more predictable world. They pick up their child and run from the places I am. Here is where I will stay, must stay, teaching my child the rules of this other world so maybe one day he’ll enter, because I know their not coming to ours.

Poetic Re-cast Four. Insiders…

Know what you say in silence.

Wait patiently while you think.

Celebrate baby steps with you.

Laugh with you, cry with you, feel frustration with you.

Try to understand even when they don’t.

Stick by you even when your child makes a scene.

Outsiders…

Want an explanation.

Stare impatiently.

Look disgusted.

Don’t hide their whispers.

And fail to realize that this could have been them.

Participant E:

Poetic Re-cast Five. Grieving is life long, lingering, intolerable, ever-present. I grieve for what my son will never be, what my family will never experience, and for the life I believed would be.

Poetic Re-cast Six. Isolation…
Unreturned phone calls.
Disappearing friends.
Absent family.
Blank stares.
Watchful eyes.
Judgment.
Fear.

Consolidating Summary

Mothers occupy two very different, yet closely related positions when it comes to their child. Participant B, Poetic Re-cast Three highlights this nicely. They love their child, but at times they hate them. They live in a world of madness but desire sanity. They want to be social, but at times at forced to be a recluse. Their primary role is to battle the uninformed and uncooperative to better the world for their child. They must continue to fight for who the child could be – if only. They acknowledge the things their child should be able to do but also understand they will always be different. Many of these conclusions are exacerbated by watchful eyes. Mothers feel shame and sometimes that their child’s behaviour is their fault. They feel judged and therefore they feel isolated. Autism is an invisible disorder. It looks like the child is misbehaving – if only people could understand the complexities behind their behaviour.

Final Consolidation of Diamond Analysis Strategy

The descriptive and narrative pieces have given structure to the analysis process and have made evident features of body, space, time and relation. The focus group provided another component which added depth and allowed for another measure of
internal consistency. Final eidetic features have become evident as a result of these three components.

Being a mother of a child with autism means that you live a complicated and contradictory existence. Many days are fraught with struggle, anticipation, watchful eyes, judgment and guilt. There is a constant battle waging; the one within themselves, and the one with the uninformed and uncooperative. Both of these are in the service of their child.

The home is supposed to symbolize our sense of being and provide sanctity where we can feel protected and ourselves (van Manen, 1990). Instead the home becomes a war zone where possessions are destroyed, rooms are obsolete, food is distributed on floors and computer tables and family relationships are constantly pushed beyond typical boundaries. Siblings must learn to live with unpredictability, uncertainty, and the realization that their things are only theirs until they are thrown out the window or into a mirror. Mothers must be everything for everyone, forced in many situations to give most of their attention to the child who rarely returns the same sentiments.

Strength is not debatable. It must be ever-present. Grieving is obvious, but must be done in the small moments of the child’s absence. It is palpable that these mothers appreciate moments of calmness, despite how mundane. It is these mundane moments that also create stress. They are monotonous and permanent with little relief. Despite this, it seems that these mothers will never stop fighting for their child, and will continue to love them despite how complicated that may be.
Discussion

Many of the eidetic features previously discussed bear remarkable resemblance to Foucault’s (1980) disciplinary practices and Wendall’s (1996) insights on the rejected body. The mothers within this study feel marginalized, watched, and surveilled. They breathe sighs of relief when their child is at school because it allows them the opportunity to feel normal. Despite living many years with their child, and coming to terms (to a certain extent) with their autism, the pressure to conform is still obvious. Sometimes, this is by going to the grocery store at 5:00 am so no one is there to watch them. Sometimes, this is avoiding a call from the professionals who continue to classify their child. Sometimes this is through lengthy discussions of boundaries and space.

*Foucault’s Disciplinary Practices*

Foucault encourages us to investigate dominant practices within a given society. Disciplinary practices are embedded with discourses and techniques. Power, in this case, disciplinary power pervades society and is used to construct the social body we live within (Foucault, 1980). The Truths found within our social body construct the laws that are used for judging, classifying and for determining our advantage or disadvantage (Foucault, 1980). As a result, these Truths become the carrier of power. There are apparent Truths about autism, but also about mothers, and more specifically about mothers who have children with autism. An investigation of this power follows – how is domination and control exerted over mothers who have children with autism?

Disciplinary power, one of Foucault’s most noted underpinnings regulates the bodies of individuals within a society through their actions and attitudes. This is often done by regulating the organization of space, time, and behaviour. Frequently, it is
enforced through a complex surveillance system. This is a concept that has become exceedingly evident throughout this piece of work. It is important to note that for Foucault (1980) power is not discipline, but rather a way that discipline can be exercised. Foucault (1980) discusses numerous techniques of power. Among them are: surveillance, space and time distribution, regulation, classification and normalization.

The first, surveillance is defined as, “supervising, closely observing, watching, threatening to watch or avoiding being watched” (Gore, 1997, p.655 as cited in Watson, 2009). This concept will be discussed in more detail in preceding sections. Space distribution is habitually used in schools to divide students to separate them into more manageable groups. Gore (1997 as cited in Watson, 2009) notes that space distribution occurs when people are divided into parts which arrange, rank and place their bodies in a certain space. Evidently, mothers of children with autism occupy a very distinct space, typically separate from those in mainstream society. Again, this is a complex situation, one that is chosen, yet not by the mothers themselves. For example, a family outing can’t just be a family outing. It becomes a time for others to watch, to judge, sometimes to show disgust. Many of these mothers expressed that there was no where for them to go and feel accepted. Often, “…it’s the small things. Like, I would love to just go to Happy Rolph’s and not have all those people there. Like have Happy Rolph’s to myself and then he can be as peculiar, odd…” (Participant D). Simply put, “It’s great to go someplace (or at least try) and not worry about weird behaviour” (Participant C).

When you have a child with autism, space is no longer just your own. It is open to everyone, for everyone, and the ability to make judgments may come too easy to those on
the outside. Not all people are judging, but their looking, and despite sometimes good intentions looking can be harmful even in the best of situations.

Time distribution on the other hand occurs through structuring time into segments. According to Gore (1997 as cited in Watson, 2009) it produces structure, routine and knowledge while regulation uses rules and restrictions to encourage people to adapt to different requirements. Often, this includes rewards and punishments. As a society, we are required to learn a multitude of rules that serve to govern our behaviour. I would argue that behavioural modification programs set up for children with autism is one of these regulating systems. Parents often have to enforce these token systems at home by enforcing certain behaviours and punishing others. Participant B discusses one of the requirements for kindergarten and how difficult, this ‘simple’ task was for her child: “---has been getting a lot of praise at school for being able to sit appropriately during carpet time (15 min). This seems like a simple task, but for --- it is a huge accomplishment” (Participant B). She also mentions the stress associated with assessment reports and how if possible she would want to avoid this all together. “The assessment reports have all been sent out. Now begins a flurry of meetings: school, doctor, daycare. Let the fun begin” (Participant B). Participant D also discusses the amount of time spent teaching her child the rules, and boundaries that are not ‘common sense’ to him, “We are spending a lot of time trying to teach --- the rules of the outside world” (Participant D).

The pressure to regulate is best expressed through this quote, “He gets very frustrated with me for being on his case. I feel like I am constantly nagging him. Clean up, listen, pay attention, keep your voice down. I feel that I am heaping negativity on him. I just get to such a level of frustration that I “snap”. I hope when he grows up he
doesn’t just remember me yelling at him (Participant B). The pressure to conform, to teach, to modify the child is obvious, but so is the stress and self doubt that comes with it.

Last, classification occurs when certain individuals or groups are separate from others (Gore, 1997 as cited in Watson, 2009). Normalizing judgment operates through a classification system of good and bad behaviour (Foucault, 1975). Individual acts are compared to, “a whole and to one another in a hierarchal, value laden construction that outlines an average, and defines the bounds of external limits. Healthy behaviours become defined in opposition to the forbidden, the shameful and the abnormal…” (Keenan, 2001, p.213). I think it is obvious that autism as a category is deviant because of classification systems. Autism is not normal, and therefore, changeable. The child cannot change themselves, and therefore it is up to mothers, sometimes both parents to seek out resources and follow through with these services to better their child – for who? Again, I am not discrediting or denying how helpful therapy can be, rather showing that therapy should come with limits and that maybe therapy is not always the solution to the problem. Even with therapy, these children still have autism. In many cases they are still going to be different. Acceptance, understanding, and teaching seems like a better alternative than eradicating, ignoring and classifying. What happens if therapy doesn’t help the child? What are they classified as now? Furthermore, what does this mean to the mother who fought through therapy and failed? Some thoughts to consider.

The Panopticon is a good example of many of these techniques. The Panopticon was originally designed for a prison in the late eighteenth century and visually is a multitude of grouped cells that are visible from a central viewing tower. This idea of the Panopticon is often used by Foucault as a metaphor for the operation of power and
surveillance (Foucault, 1980). Foucault (1977) states, “He who is subjected to a field of visibility and who knows it, assumes responsibility for the constraints of power, he makes them play spontaneously upon himself, he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection” (p. 202). Although the Panopticon originated in a prison the ideas central to it are utilized to manage entire populations.

Arguably, many, if not all of the mothers within this study feel imprisoned. Of course, much of this comes from the opinions they feel from outsiders. One mother noted, “Other people’s opinions? I feel a lot of shame. I feel a lot of eyes on me. I have had to just work past that and focus on my kids but umm, I feel there’s a lot of explaining to do. I just stopped explaining to grocery clerks who don’t need to know and just the core people. It’s a lot of pressure” (Participant D). However, it would be impossible to argue that society alone creates this dynamic. It is a bidirectional relationship that feeds off each other. Mothers feel alone, watched, judged and therefore, their desire to segregate themselves and their child increases. In many cases, they also seek out more resources or attempt to normalize their child’s behaviour to decrease the pressure they feel from the outside.

Participant A describes living in a subdivision where houses are closely linked together – “That’s like with my son --- because our houses are close together and this year as I was telling you how he’s been difficult this year because he’s in puberty. Well, he was getting up at night banging on his door and the walls and this would be going on all night. We were exhausted. This went on for about 3 months. I was upping his meds during this period, and umm... so a few weeks. It was maybe 3 weeks later, my neighbour
comes over and my husband was cleaning out the car. He goes, ‘is everything alright over there?’ They could actually hear the banging. They probably thought we were beating --- or something. No, it’s just ---. Oh my god. If they can hear it, it was probably keeping them up at night” (Participant A). Similarly, Participant D comments, “I want to live in the country because I can’t take it anymore. I want to look through the windows and not feel everyone’s saying, ‘ohh there are those --- people again’ (Participant D).

Central to Foucault’s (1975) idea of a ‘disciplinary’ society are three modes of control: hierarchical observation, normalizing judgment, and the examination. Families who have children with autism experience, “a principle of compulsory visibility” (Foucault, 1975, p.187), as their thoughts, behaviours and choices are routinely exposed and dissected. A mother within this study describes getting up and going to the grocery store at 5:00 am because no one is there to watch her child at that time. “We find we get up and get at it and attack the world early in the morning because the crowds aren’t there, and they know us at the grocery store now. You know what I mean like, it doesn’t take too long til people recognize us” (Participant D).

As evident with this study, control over people can be obtained by simply observing them. For example, seats in a stadium make it easy for spectators to see but also allow guards or security cameras to quickly and efficiently scan the audience. The goal of disciplinary control is to correct deviant behaviour, so that society is living by the set standards or norms (Foucault, 1975). Therefore, disciplinary control is concerned with what people have not done or their failure to reach the required standards (Foucault, 1975). This ‘normalization’ is increasingly evident in our society. The rigorous programming for children with autism, as well as the pressure to document the child’s
journey to ‘normal’ is a concrete example of this. These documents provide another
venue for control as they are often used to compare categories, averages, and norms.

Returning again to the idea of the Panopticon - central to this idea is the notion
that although guards would not being watching the prisoners at all times, they could be.
Control is utilized because prisoners realize that at any time they could be watched,
therefore they must always act as though they are being observed (Foucault, 1975). This
idea can be applied to many different systems of power.

The mothers within this study are a primary example of how Foucault’s
disciplinary practices work. It is evident that they feel the gaze from society and as a
result attempt to monitor their and their child’s behaviour. Although in most cases, the
ability to normalize the child’s behaviour is not possible. Participant D states, “I am
trying to learn to enjoy the successes and not feel so low when he has a challenging day. I
know in my head that it is NOT MY FAULT, but it is hard to convince my heart and my
neighbors. Ha”!

Wendall’s Insights on the Rejected Body and An Exploration of the Mundane

Wendall (1996) discusses the social construction of disability and the
circumstances that determine standards of normality. Mothers of children with autism are
not disabled, but by association they often face the same barriers and boundaries that
their child does. The mothers within this society interact with medical professionals much
more often than mothers of non-disabled children. Despite these interactions, it is rare
that mother’s opinions are shared in research or acknowledged as inherently useful.
Mothers themselves are often held to an unattainable standard of normality. These beliefs
are often internalized by mothers, and shown through the blood, sweat and tears of
fighting for their child. Mothers of children with autism are often more aware of these standards of classification, and normalcy because they fall outside of them or because they are fighting to maintain their place within them.

Most people would agree that being ousted or cast as different is difficult. Especially difficult when it is your child; your own flesh and blood. Mothers often take on the role of patient advocate, guard, protector, teacher and nurturer. This is especially true for children with autism. As of late, their have been discussions of cures, recovery and vast improvements. Mothers understand that they can control their behaviour, but they cannot control their child’s. These findings provide hope for change, hope for normalcy, and hope for acceptance. Often, though I question at what cost? Does this choice cost the mother herself? Does this choice cost the child their very beingness? Many would argue that autism is not an appropriate way to be, but, who gets to decide that? The mother’s bodies are subjected to the pressure that comes with these beliefs. Of course she wants the best for her child. Of course she would like things to be a bit easier. However, we need to question the costs of such decisions – to the mother, to the family, to the child.

Wendall (1996) believes that the social barriers surrounding disability contribute to the medical diagnosis. Often subtle cultural and social barriers include some and exclude others. As a result, full participation within society is hindered. Sometimes this happens by those who are unwilling to create the opportunity for those who are unable to be able. Sometimes, this happens because of the felt stigma that mother’s experience. Either way, as stated above this is a bidirectional relationship. What is noticeable is how attuned mothers are to this. They realize there are many places they can’t or won’t take
their child. They realize others observe them, watch them, and sometimes judge them. They realize their children are not getting the same opportunities as many other children. So, they work harder, fight harder, and spend more time. Their stress, albeit in the most mundane ways is palpable.

Sadly, it seems there are few people who these mothers feel recognize their struggle, without pity, without judgment and try to understand even when they don’t. Participant D states, “I don’t expect anyone to be any certain way with him but I don’t feel like she wants to knock him into next week and I feel that a lot of times with people because he is so wild, like he’s a wild child, that I don’t want people to hate him and she adores him, and the things that he says she is amused by and she can’t wait to tell me. I feel safe and comfortable. We thought about respite care, but I really worry about him getting abused. He is very difficult” (Participant D).

Stress encompasses many different facets of these mothers’ lives. It comes from the unpredictability of living with a child with autism, but also from seemingly mundane daily events that still require attention, autistic child or not. Participant B describes that, “some nights are easy and some are a nightmare (no pun intended). He will scream at my husband and I, tell us that he hates us and wants to live somewhere else. After working all day it is hard to keep my emotions in check. I am tired and want to spend quality time with him. I try to please but my efforts go unrewarded” (Participant B). In some cases, violence permeates daily life, an added daily anxiety. “I was helping him get his stuff and he hauled off and hit me in the head. As happy as I am to see him, I sometimes wonder if it’s worth going away at all. I find it very difficult to get back into the routine of dealing
with him. I try not to take it personally that he hits me but it’s really hard to keep a ‘thick skin’ about it” (Participant C).

Many of these mothers have other children, extended families, and friends who can complicate the already complicated life of having a child with autism. I think most of the mothers feel like they can never give enough, and there is never enough time in the day. In some situations having family and friends makes things easier, in some it makes the situation more complicated. For example, grandmothers choose to have seven glass top tables instead of creating a safe, protected place for her grandchildren to play, siblings have to watch their mothers being physically attacked by their brother and friends slowly drift away. All too often, this is the reality of living with a child with autism.

One mother expresses the difficulty of having other children, “…she is very motherly of him unless she just can’t take it anymore. And then she just bubbles over and freaks out which is okay it needs to now and then but my 2 year old doesn’t get it at all. She is very frustrated, she’s very angry but I’m curious to see how that’s going to go so we’re trying to put in place that she gets enough space and her own time so she’s not always frustrated. So, she doesn’t grow up angry and hostile” (Participant D). Siblings growing up without hostility and anger is particularly important, as they will play an integral role in their siblings life once their parents are gone. These parents understand the reality that their other children face, and, “…make a point of not saying that you’re not responsible for your brother because you are. They don’t have to be his caregiver, but I’m never going to say you’re not responsible for him cause that’s not fair, because that’s not the truth” (Participant C). Needless, to say it’s complicated, and hard to understand from the outside. These mothers realize what is expected of them, and also of their
children – autism or not. Truths have to become truths quickly, because the reality of the situation is laid out for everyone to see. The decisions made are scrutinized, questioned and judged. Despite this, these mothers continue to do what is best for their family and their child, and are attempting to do this despite and within relatively damning outside conceptions of who they are and how they parent.
Implications and Limitations

This thesis takes some initial steps in examining the lives of mothers who have children with autism. I believe that this research has put value in mothers’ words, thoughts and insights. Readers were provided a close encounter with these mothers’ realities, and I hope this has allowed them to step inside an experience they otherwise would not have been able to. Future research needs to delve deeper into mothers’ experiences while also exploring alternative constructions of motherhood. Engaging fathers in a similar study is also encouraged. It may be interesting to look at a comparison of mothers and fathers experiences of raising children with disabilities.

As with any study, this study has limitations. My knowledge about mothering comes from both psychology and disability literature but not from other orientations. My knowledge is mostly based in my own western socialization of valorized motherhood. As a result, I have a primarily North American bias, as this is where most of my literature arose from and this is also where I selected my informants. These mothers journaled once a week for a period of month once. Therefore, I collected four journal entries from each. Perhaps more entries would have yielded more or different examples to work with. Last, in the focus group all the mothers knew eachother and perhaps this familiarity led them to use ‘short hand’ when discussing particular incidents or places. People who were strangers to eachother may have provided more details.
Conclusion

This subject is well researched quantitatively, it is extremely under researched qualitatively. Specifically, I have focused on mothers’ experiences of raising a child with autism, through excerpts from journals and focus group participation. A recursive, reductive approach constructed through the use of Amedeo Giorgi’s descriptive approach and Max van Manen’s hermeneutic approach brought richness and detail to the data analysis. As a researcher, reading, re-reading and careful attunement to the participants words were pertinent, as well letting the words of the mothers speak in the descriptions and re-casts of the descriptions. Re-casting poetically helped to bring the reader closer to the story, as well as point out specific characteristics of the mothers’ experience.

The relationship between a mother and her child is complex. This relationship intensifies in complexity when you have a child with autism. You learn to live with unpredictability, but also routine. You be increasingly aware of awkward stares, or disapproving glances. You learn that complication, anticipation and patience are part of everyday, despite the fact that calmness, clarity, focus and attunement must also be. Normality doesn’t exist, it least not in the presence of the child. In many cases, it was evident that these mothers were striving for normalcy, if only a little bit, for themselves, and their children. Typical parents may not be aware of the mundane, the usual, and the simple because they think it will always be there, but for these mothers they know it may not be.

This paper has also explored how Foucault’s disciplinary practices and Wendall’s discussion on the rejected body, parallel some of the experiences mothers of children with autism encounter. In many cases, mothers were feeling watched, surveilled and
judged. Foucault encourages the deconstruction of dominant practices as well as taken for granted Truths within society. There are apparent Truths about autism, but also about mothers, and more specifically about mothers who have children with autism. Disciplinary power and its components bare strong resemblance to many of the feelings expressed by mothers. Surveillance, space distribution, regulation, classification and normalization permeated these mother’s words. I am not arguing that society alone creates feelings of surveillance and imprisonment. It is a bidirectional relationship – mothers feel alone, watched, judged and therefore, their desire to isolate themselves and their child increases.

Zelan (2003) states, “In our quantifying society, where we grasp ever more assiduously for the mythical norm, we have forgotten how to enjoy human differences. Measuring, labeling, and evaluating others had led us either to eschew human variation or to become alarmed by it...If only we would focus as much on the worked-with and lived-with child as we do on the theorized and tested child” (p.386). It is my hope that this is what I have done, by asking, and not telling, by writing, and not quantifying, by appreciating and acknowledging.
References


Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H., Dawson, G., Gordon, B.,


Appendix A

Information Letter

Acknowledging Mother’s Lived Experience of Raising a Child with Autism: A Phenomenological Inquiry

Brock University

December 17, 2008

Dear Potential Participant:

I am a Master’s student in the Department of Child and Youth Studies at Brock University conducting research under the supervision of Professor Maureen Connolly, Professor Hans Skott-Myhre, and Professor Tony Volk. I am researching the day to day lived experiences of mothers who are raising children with autism.

Little research has asked mothers specifically about what is going on in their day to day lives. This important piece of information is missing from prominent literature. Given that mothers often take on the role of primary caregiver and spend a large portion of their time with their children, it is mothers who are able to offer a different representation of what autism is like.

As a potential participant you have been provided with my contact information. If you wish to participate in this study, please contact myself, Jamie Posavad through the information you were provided with. After contacting the researcher, you will be invited to participate in two phases of this project, which are detailed below. After your participation has ended you will be provided with a feedback letter to inform you what the full analysis revealed.

As noted above, there are two phases to this project. In the first phase, over a one month period, you will be invited to journal your experience of living with your child. This will be done four times over a month period. It is at your own discretion how much you write and what you write about. In the second phase of the study, a focus group will bring all the participants together to discuss the initial outcomes of the journals. There will be approximately 5-8 other mothers participating in this phase of the study. This portion will be audio and video recorded to ensure accuracy. It is important to note that participation in this study will extend over a duration of approximately 4 months.

All the information that you provide through your participation in this study will be kept confidential. Only the researcher, Jamie Posavad, as well as the advisory committee, Maureen Connolly, Hans Skott-Myhre and Tony Volk will have access to the data. Further, you will not be identified in the thesis or in any report or publication based on this research. It is also important to note that your anonymity will be secured through the journaling process, however, during the focus group you will be known to the researcher.
and other participants. It is at your own discretion how much personal information you disclose.

Although this study may include psychological risks given that we are discussing a potentially sensitive issue, they are no more that what could be incurred in daily life. The data collected through the journals will be returned to you upon analysis, while the audio and video tapes will be destroyed. All other data collected will be kept for a period of five years in a secure location. A feedback letter is planned on completion of the full analysis to provide you with an opportunity to learn about one another’s experiences, strength and hope. If the research is published you will be notified through phone correspondence.

If after receiving this letter, you have any questions about this study, or would like additional information to assist you in reaching a decision about participating, please feel free to contact Maureen Connolly at 905-688-5550 ext.3381, or myself, Jamie Posavad at 905-802-4193 or through email at jp03bn@brocku.ca. I would like to encourage you to keep a copy of materials, such as the information and consent forms for yourself.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at Brock University. However, the final decision about participation is yours, as participation is completely voluntary. Should you have any comments or concerns resulting in your participation in this study, please contact the Office of Research Ethics at 905-688-5550 ext. 3035.

Please also note that this letter includes a list of qualified professionals who specialize in dealing with parental stress, in case you feel you need assistance.

Thank you in advance for your co-operation in my research.

Yours Sincerely,

Jamie Posavad

---

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (File # 08-105). For more information please contact the Research Ethics Officer at 905-688-5550 ext. 3035.
Appendix B

Consent Form

Acknowledging Mother’s Lived Experiences of Raising a Child with Autism: A Phenomenological Inquiry

I have read the information presented in the information letter about a study being conducted by Jamie Posavad of the Department of Child and Youth Studies at Brock University. I have had the opportunity to ask questions related to this study, to receive satisfactory answers to my questions, as well as any other additional details I wanted.

I am aware that I will be participating in this study for a period of approximately 4 months. My participation during the focus groups will involve the attendance of 5-8 other parents. I therefore understand that my participation will involve speaking to and listening to other mothers share their experiences of raising a child with autism.

I am aware that excerpts from my journals and/or focus group transcriptions may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I was also informed that my participation in the focus group involves audio and video recording. The researcher has informed me that only she, as well as the research team will have access to the data.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher. I was also informed that my participation in this study is voluntary.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at Brock University. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Office of Research Ethics at 905-688-5550 ext.3035. Please note that it is advised that you keep a copy of the consent form for your own records. In addition, on the following page you will find a list of qualified professionals who specialize in dealing with parental stress, in case you feel you need assistance.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

☐ YES  ☐ NO

I agree to participate in the focus group which involves audio and video recording.

☐ YES  ☐ NO
I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐ YES    ☐ NO

Participant Name: ___________________________ (Please print)

Participant Signature: ________________________

Witness Name: _______________________________ (Please print)

Witness Signature: ____________________________

Date: ________________________________________

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (File # 08-105). For more information please contact the Research Ethics Officer at 905-688-5550 ext. 3035.
Appendix C

Telephone Script

Hello, may I speak to ________________.

Hi, this is Jamie Posavad calling; I am a Master’s student at Brock University in the Department of Child and Youth Studies. The reason I am calling is that I am conducting a study on mothers who have children with autism. I would like to look at the day to day lived experiences that evolve as a result of having a child with autism to gain a greater understanding of what mothers experience while also working together to potentially solve some of these issues. I am currently seeking participants, and I wondered if you would be interested in hearing more about it?

[If not] Thank you, good-bye.

[If yes] This study involves completing a journal over a period of a month that illustrates what it is like to live with a child with autism. You will be invited to complete this journal once a week, for the month, therefore, completing four descriptions. The topic and the amount written is completely up to you. At this end of this period you will be invited to participate in one focus group session with the other mothers participating in the study.

Participation in this study will occur over a period of 2-4 months, and involve approximately 6-10 hours of your time.

I would like to assure you that this study has been reviewed and received ethics clearance from the Office of Research Ethics. However, the final decision to participate is yours.

Would you be interested in participating?

[If no] Thank you for your time. Good-bye.

[If yes] Thank you. I sincerely appreciate your interest in my research.

Do you have any questions you would like answered?

Would I be able to mail you the information and consent letter? I will also provide you with a stamped envelope to return them.

Is there a day or time that works best to contact you after I have received your consent to participate?

Great. Thank you. We will be speaking soon. If you have any questions or concerns between now and then please feel free to contact me at 905-802-4193 or through email at jp03bn@brocku.ca
This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (File # 08-105). For more information please contact the Research Ethics Officer at 905-688-5550 ext. 3035.
The following is completed for two of mother’s journals: specific and general descriptions, strong words, body, space, time, relation, and poetic recast.

The following is completed for all of mother’s journals: strong words and phrases, body, space, time, relation, and poetic recast.

Descriptive (Full Array)

Narrative

Eidetic Features

Internal Cross Check

Eidetic Features

Eidetic Features
Brock University Research Ethics Board (REB)

Application for Ethical Review of Research Involving Human Participants

Please refer to the documents “Brock University Research Ethics Guidelines”, which can be found at http://www.brocku.ca/researchservices/, prior to completion and submission of this application.

If you have questions about or require assistance with the completion of this form, please contact the Research Ethics Office at (905) 688-5550 ext. 3035, or reb@brocku.ca.

Return your completed application and all accompanying material in triplicate to the Research Ethics Office in MacKenzie Chown D250A.

Handwritten Applications will not be accepted.

Please ensure all necessary items are attached prior to submission, otherwise your application will not be processed (see checklist below).

No research with human participants shall commence prior to receiving approval from the research ethics board.

---

**DOCUMENT CHECKLIST**

3 complete sets of the following documents (one original + 2 copies) if applicable

<table>
<thead>
<tr>
<th>Recruitment Materials</th>
<th>Consent Materials</th>
<th>Data Gathering Instruments</th>
<th>Feedback Letter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Letter of invitation</td>
<td>Consent form</td>
<td>Questionnaires</td>
<td>Letter of Approval for research from cooperating organizations, school board(s), or other institutions</td>
</tr>
<tr>
<td>Verbal script</td>
<td>Assent form for minors</td>
<td>Interview guides</td>
<td>Any previously approved protocol to which you refer</td>
</tr>
<tr>
<td>Telephone script</td>
<td>Parental/3rd party consent</td>
<td>Tests</td>
<td>Request for use of human tissue sample in research</td>
</tr>
<tr>
<td>Advertisements (newspapers, posters, SONA)</td>
<td>Transcriber confidentiality agreement</td>
<td></td>
<td>Please Note: this form is required for all research projects involving human tissue, bodily fluids, etc.</td>
</tr>
<tr>
<td>Electronic correspondence guide</td>
<td></td>
<td></td>
<td>Signed Application Form</td>
</tr>
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Research Ethics Office

- Brock University
- 500 Glenridge Ave
- St. Catharines, ON
- L2S 3A1
- Fax: 905-688-0748
SIGNATURES

PLEASE NOTE: The title "principal investigator" designates the person who is "in charge" of the research. In this position, the principal investigator is assumed to have the abilities to supervise other researchers, be responsible for the financial administration of the project, have the authority to ensure that appropriate guidelines and regulations are followed, and be competent to conduct the research in the absence of faculty supervision. The restriction of the term "principal investigator" to faculty or post-doctoral fellows does not have implications for ownership of intellectual property or publication authorship. Given the above consideration, a student cannot be identified as a "principal investigator". However, for the purpose of recognizing a student’s leadership role in the research, a faculty member may designate a "principal student investigator" below.

INVESTIGATORS:

Please indicate that you have read and fully understand all ethics obligations by checking the box beside each statement and signing below.

☐ I have read Section III: 8 of Brock University's Faculty Handbook pertaining to Research Ethics and agree to comply with the policies and procedures outlined therein.
☐ I will report any serious adverse events (SAE) to the Research Ethics Board (REB).
☐ Any additions/changes to research procedures after approval has been granted will be submitted to the REB.
☐ I agree to request a renewal of approval for any project continuing beyond the expected date of completion or for more than one year.
☐ I will submit a final report to the Office of Research Services once the research has been completed.
☐ I take full responsibility for ensuring that all other investigators involved in this research follow the protocol as outlined in this application.

Principal Investigator

Signature ____________________ Date: ____________

Principal Student Investigator (optional)

Signature ____________________ Date: ____________

Co-Investigators:

Signature ____________________ Date: ____________
Signature ____________________ Date: ____________

FACULTY SUPERVISOR:

Please indicate that you have read and fully understand the obligations as faculty supervisor listed below by checking the box beside each statement.

☐ I agree to provide the proper supervision of this study to ensure that the rights and welfare of all human participants are protected.
☐ I will ensure a request for renewal of a proposal is submitted if the study continues beyond the expected date of completion or for more than one year.
☐ I will ensure that a final report is submitted to the Office of Research Services.
☐ I have read and approved this application and proposal.

Signature ____________________ Date: ____________
SECTION A – GENERAL INFORMATION

1. Title of the Research Project: Acknowledging Mother’s Lived Experiences of Raising a Child with Autism: A Phenomenological Inquiry

2. Investigator Information:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position (e.g., faculty, student, visiting professor)</th>
<th>Dept./Address</th>
<th>Phone No.</th>
<th>E-Mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal Investigator</td>
<td>Jamie Posavad</td>
<td>Master’s Candidate in CHYS</td>
<td>905-689-8534</td>
<td><a href="mailto:jp03bn@brocku.ca">jp03bn@brocku.ca</a></td>
</tr>
<tr>
<td>Co-Investigator(s)</td>
<td>Maureen Connolly</td>
<td>Faculty</td>
<td>905-688-5550 Ext. 3381</td>
<td><a href="mailto:mconnoll@brocku.ca">mconnoll@brocku.ca</a></td>
</tr>
<tr>
<td></td>
<td>Hans Skott-Myhre</td>
<td>Faculty</td>
<td>905-688-5550 Ext. 4323</td>
<td><a href="mailto:hans.skott-myhre@brocku.ca">hans.skott-myhre@brocku.ca</a></td>
</tr>
<tr>
<td></td>
<td>Tony Volk</td>
<td>Faculty</td>
<td>905-688-5550 Ext. 5368</td>
<td><a href="mailto:tony.volk@brocku.ca">tony.volk@brocku.ca</a></td>
</tr>
</tbody>
</table>

3. Proposed Date of commencement: [ ] upon approval, OR [ ] other. Please provide date (dd/mm/yyyy) __________

   Proposed Date of completion (dd/mm/yyyy): 01/08/2009

4. Indicate the location(s) where the research will be conducted:

   - Brock University
   - Community Site
   - School Board
   - Hospital
   - Other

   Specify within participants homes

5. Other Ethics Clearance/Permission:

   (a) Is this a multi-centered study? [ ] Yes [ ] No
   (b) Has any other University Research Ethics Board approved this research? [ ] Yes [ ] No

   If YES, there is no need to provide further details about the protocol at this time, provided that all of the following information is provided:
   - Title of the project approved elsewhere: __________
   - Name of the Other Institution: __________
   - Name of the Other Board: __________
   - Date of the Decision: __________

Research Ethics Office
- Brock University
- 500 Glenridge Ave
- St. Catharines, ON
- L2S 3A1
- Fax: 905-688-0748
A contact name and phone number for the other Board: _____

Please provide a copy of the application to the other institution together with all accompanying materials, as well as a copy of the clearance certificate / approval.

If NO, will any other University Research Ethics Board be asked for approval?  □ Yes □ No

Specify University/College _____

(c) Has any other person(s) or institutions granted permission to conduct this research?  □ Yes □ No

If yes, specify (e.g., hospital, school board, community organization, proprietor) provide details and attach any relevant documentation. _____

If NO, will any other person(s) or institutions be asked for approval?  □ Yes □ No

Specify (e.g., hospital, school board, community organization, proprietor) _____

6. Level of the Research:

□ Undergraduate Thesis  □ Masters Thesis/Project  □ Ph.D

□ Post Doctorate  □ Faculty Research  □ Administration

□ Undergraduate Course Assignment  □ Graduate Course Assignment  □ Other (specify course) _____

(specify course) _____

7. Funding of the Project:

(a) Is this project currently being funded  □ Yes □ No

(b) If No, is funding being sought  □ Yes □ No

If Applicable:

(c) Period of Funding (dd/mm/yyyy): From: ______ To: ______

(d) Agency or Sponsor (funded or applied for)

□ CIHR  □ NSERC  □ SSHRC  □ Other (specify): ______

(e) Funding / Agency File # (not your Tri-Council PIN) ______

8. Conflict of Interest:

(a) Will the researcher(s), members of the research team, and/or their partners or immediate family members receive any personal benefits related to this study – Examples include financial remuneration, patent and ownership, employment, consultancies, board membership, share ownership, stock options. Do not include conference and travel expense coverage, possible academic promotion, or other benefits which are integral to the general conduct of research.

□ Yes □ No

If Yes, please describe the benefits below.

(b) Describe any restrictions regarding access to or disclosure of information (during or at the end of the study) that the sponsor has placed on the investigator(s).

SECTION B – SUMMARY OF THE PROPOSED RESEARCH
9. Rationale:

Briefly describe the purpose and background rationale for the proposed project, as well as the hypothesis(es)/research question(s) to be examined.

Autism is a chronic, lifelong condition. It is a constantly changing disorder; one that requires adaptation and strategic coping methods. Given the characteristics of autism, and the treatment it requires, the entire families’ life is often greatly affected. Before parents can even deal with the diagnosis of autism they have to become therapist, chauffeur, and case manager, all while trying to be a husband or wife, and parent to their other children. More specifically, mothers are more often emotionally and physically stressed given that they, more often than not, take on the role as primary caregiver.

Phenomenological inquiry, a technique used to uncover meaning, will attempt to articulate the day to day lived experiences of mothers who have children with autism. Using a reductive, recursive lens the focus will not only be on understanding the day to day lives of mothers who have children with autism but also working as a team to develop a greater understanding of what can be done to better manage or solve issues occurring as a result of having a child with autism. By articulating these lived experiences a narrative will develop around the essences of experiences occurring in mother’s lives. By better understanding areas of strength and weakness, and gaining insight into this particular phenomenon, we are better able to serve mothers which bi-directionally serves the needs of children.

10. Methods:

Are any of the following procedures or methods involved in this study?

- Questionnaire (mail)
- Questionnaire (email/web)
- Questionnaire (in person)
- Interview(s) (telephone)
- Interview(s) (in person)
- Secondary Data
- Computer-administered tasks
- Focus Groups
- Journals/Diaries/Personal Correspondence
- Audio/video taping specify)
- Observations
- Invasive physiological measurements (e.g. venipuncture, muscle biopsies)
- Non-invasive physical measurement (e.g., exercise, heart rate, blood pressure)
- Analysis of human tissue, body fluids, etc. (Request for Use of Human Tissue Sample must be completed and attached)
- Other: (specify) ____

Describe sequentially, and in detail, all of the methods involved in this study and all procedures in which the research participants will be involved (paper and pencil tasks, interviews, questionnaires, physical assessments, physiological tests, time requirements, etc.)

Attach a copy of all questionnaire(s), interview guides or other test instruments. If reference is made to previous protocols, please provide copies of relevant documentation.

Participants will be asked to complete the question: Describe the day to day experiences of living with a child with autism. This will be completed through a paper and pencil task. Over a one month period, mothers will be asked to write about their experiences of living with a child with autism. They can write as much or as little as they like, and the topic is completely up to them. However, each participant will be required to write once a week for a month, therefore completing four descriptions. In addition, participants will be asked to participate in a focus group that follows up on the information collected from their descriptions. A content level analysis/first reduction will be conducted using specific and general themes as articulated by Giorgi (1985) as well as existential themes articulated by vanManen (1996).

11. Professional Expertise/Qualifications:

Does this procedure require professional expertise/recognized qualifications (e.g., registration as a clinical psychologist, first aid certification)?

- Yes  specify: ____  ■ No
If YES, indicate whether you, your supervisor, or any members of your research team have the professional expertise/recognized qualifications required? □ Yes □ No

12. Participants:

Describe the number of participants and any required demographic characteristics (e.g., age, gender).

Participants must be female, and the mothers of a child(ren) or adolescent(s) with autism. The child or adolescent can be any age and with varying degrees of autism spectrum disorder. This may also include children with Asperger’s Syndrome.

13. Recruitment:

Describe how and from what sources the participants will be recruited, including any relationship between the investigator(s), sponsor(s) and participant(s) (e.g., family member, instructor-student; manager-employee).

Attach a copy of any poster(s), advertisement(s) and/or letter(s) to be used for recruitment.

The participants will be recruited through the Autism Spectrum Disorders (ASD) Summer Camp from parents whose children have attended the camp. The parents will initially be contacted through telephone (Appendix A).

The participants will be recruited through the Autism Spectrum Disorders (ASD) Summer Camp. I will leave my contact information with the Director of the camp, who will then pass it on to parents whose children attend the camp. Interested parents then have the opportunity to contact the researcher. The initial telephone conversation will be guided through a script (Appendix A).

14. Compensation:

a) Will participants receive compensation for participation? □ Yes □ No

b) If yes, please provide details.

SECTION C – DESCRIPTION OF THE RISKS AND BENEFITS OF THE PROPOSED RESEARCH

15. Possible Risks:

1) Indicate if the participants might experience any of the following risks:

a) Physical risks (including any bodily contact, physical stress, or administration of any substance)? □ Yes □ No

b) Psychological risks (including feeling demeaned, embarrassed worried or upset, emotional stress)? □ Yes □ No

c) Social risks (including possible loss of status, privacy, and / or reputation)? □ Yes □ No

d) Are any possible risks to participants greater than those that the participants might encounter in their everyday life? □ Yes □ No

e) Is there any deception involved? □ Yes □ No

Research Ethics Office
Brock University 500 Glenridge Ave St. Catharines, ON L2S 3A1 Fax: 905-688-0748
f) Is there potential for participants to feel obligated to participate or coerced into contributing to this research (because of regular contact between participants and the researcher, relationships that involve power-dynamics, etc.)?  □ Yes  □ No

2) If you answered Yes to any of 1a – 1f above, please explain the risk.

Given that participants will be discussing a potentially sensitive issue, psychological risks are involved. Many parents may feel overwhelmed with raising a child with autism and writing about these issues may bring them to the forefront. It may force mothers to deal with issues that are particularly sensitive or upsetting. In addition, simply finding the time to write may be an added stressor.

3) Describe how the risks will be managed and include the availability of appropriate medical or clinical expertise or qualified persons. Explain why less risky alternative approaches could not be used.

Although writing and discussing their day to day experiences may raise issues of stress, they may also alleviate stress. Writing about an experience or talking about it with other parents may serve as a therapeutic experience, rather than a stressful one. Going to the source (mothers) is the only way to collect information that is directly related to the issue. Only the person who is living that life can write about it, therefore in order to understand what is happening in the lives of mothers who have children with autism, I need to go directly to the source. Participants will understand that is they are uncomfortable at any time, they are able to leave the study with no questions asked. In addition, referrals for professionals qualified to deal with parental anxiety/stress will be readily accessible to parents who feel they need them.

16. Possible Benefits:

Discuss any potential direct benefits to the participants from their involvement in the project. Comment on the (potential) benefits to the scientific community/society that would justify involvement of participants in this study.

Mothers will benefit first by writing about their experience and second by getting the chance to discuss issues of stress or difficulty with other mothers in similar situations. The experience may serve as a support network for parents therefore alleviating stress and helping them to cope with the day to day needs of their children better. Given that there is little, is any, research on the day to day experience of raising a child with autism, this study will hopefully inform the community, which in turn may affect the way in which services are run. If anything, it may give mothers not involved in this study a voice. A voice to speak openly about their child, their experience and both the joys and hardships they experience.

SECTION D – THE INFORMED CONSENT PROCESS

17. The Consent Process:

Describe the process that the investigator(s) will be using to obtain informed consent. Include a description of who will be obtaining the informed consent. If there will be no written consent form, explain why not.

For information about the required elements in the letter of invitation and the consent form, as well as samples, please refer to: http://www.brocku.ca/researchservices/forms/index.php

If applicable, attach a copy of the Letter of Invitation, the Consent Form, the content of any telephone script, and any other material that will be utilized in the informed consent process.

Informed consent will be obtained from the participants following the reading of the Information Letter and agreement to participate. Please refer to Appendix

18. Consent by an authorized party:

Research Ethics Office
Brock University  500 Glenridge Ave  St. Catharines, ON  L2S 3A1  Fax: 905-688-0748
If the participants are minors or for other reasons are not competent to consent, describe the proposed alternative source of consent, including any permission form to be provided to the person(s) providing the alternative consent.

<table>
<thead>
<tr>
<th>19. Alternatives to prior individual consent:</th>
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<tr>
<td>If obtaining individual participant consent prior to commencement of the research project is not appropriate for this research, please explain and provide details for a proposed alternative consent process.</td>
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<tr>
<th>20. Feedback to Participants:</th>
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<tr>
<td>Explain what feedback/information will be provided to the participants after participation in the project. This should include a more complete description of the purpose of the research, and access to the results of the research. Also, describe the method and timing for delivering the feedback.</td>
</tr>
<tr>
<td>A feedback letter is planned on completion of the full analysis to provide mothers an opportunity to learn about one another’s experience, strength, and hope. This is in keeping with the earlier purpose of participants sharing and developing strategic coping methods. The sharing of feedback hopefully will assist mothers in better managing the day to day needs of the child.</td>
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<th>21. Participant withdrawal:</th>
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<tbody>
<tr>
<td>a) Describe how the participants will be informed of their right to withdraw from the project. Outline the procedures that will be followed to allow the participants to exercise this right.</td>
</tr>
<tr>
<td>The information and consent letter informs participants that there withdrawal from the study at any time can be exercised with no penalty to the participant.</td>
</tr>
<tr>
<td>b) Indicate what will be done with the participant’s data should the participant choose to withdraw. Describe what, if any, consequences withdrawal might have on the participant, including any effect that withdrawal may have on participant compensation.</td>
</tr>
<tr>
<td>Participant data will be shredded upon withdrawal from the study. There are no consequences or effects from withdrawing from the study. Given that no compensation is being given, there is no effect in this area.</td>
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**SECTION E – CONFIDENTIALITY & ANONYMITY**

**Confidentiality:** information revealed by participants that holds the expectation of privacy. This means that all data collected will not be shared with anyone except the researchers listed on this application.

**Anonymity of data:** information revealed by participants will not have any distinctive character or recognition factor, such that information can be matched (even by the researcher) to individual participants. Any information collected using audio-taping, video recording, or interview cannot be considered anonymous. Please note that this refers to the anonymity of the data itself and not the reporting of results.

| 22. Given the definitions above: |
a) Will the data be treated as confidential?  □ Yes □ No
b) Are the data anonymous?  □ Yes □ No

c) Describe any personal identifiers that will be collected during the course of the research (e.g., participant names, initials, addresses, birth dates, student numbers, organizational names and titles etc.). Indicate how personal identifiers will be secured and if they will be retained once data collection is complete.

Real names will be coded for reporting purposes but names will be known to the researcher and potentially the research supervisors. The journaling will take place within the participant’s homes where they will be unknown to each other. However, in the focus group participants will be aware of each other, as they will take place at Brock University in a private, neutral meeting room. It is at their own discretion how much information they reveal about themselves, their families and their child. Personal identifiers are secured because only the research team has access to the journals. Upon data completion the journals will be returned to the participants.

d) If any personal identifiers will be retained once data collection is complete, provide a comprehensive rationale explaining why it is necessary to retain this information, including the retention of master lists that link participant identifiers with unique study codes and de-identified data.

No data will be retained upon completion of the study.

e) State who will have access to the data.

Only the research team will have access to the data (Jamie Posavad, Maureen Connolly, Hans Skott-Myhre, and Tony Volk).

f) Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

In order to ensure confidentiality participants names will be coded in the transcription process. In addition, participant’s journals will be returned upon completion, and the tapes used in the focus groups will be destroyed following analysis. Finally, there is limited access to the data as only four people will have access to the data.

g) If participant anonymity and/or confidentiality is not appropriate to this research project, explain, in detail, how all participants will be advised that data will not be anonymous or confidential.

The letter of consent will inform participants that they will be known to the researcher and research team only through their journal submissions. However, these will be coded during the analysis process. Additionally, the focus group does not allow for anonymity or confidentiality because the participants will be known to each other.

h) Explain how written records, video/audio tapes, and questionnaires will be secured, and provide details of their final disposal or storage, including how long they will be secured and the disposal method to be used.

Upon completion of the research process, the journals will be returned to the participants. Participant data will only be kept during the analysis process. The video and audio recordings will be destroyed upon completion of the study.

SECTION F -- SECONDARY USE OF DATA

23.

a) Is it your intention to reanalyze the data for purposes other than described in this application?
b) Is it your intention to allow the study and data to be reanalyzed by colleagues, students, or other researchers outside of the original research purposes? If this is the case, explain how you will allow your participants the opportunity to choose to participate in a study where their data would be distributed to others (state how you will contact participants to obtain their re-consent)

c) If there are no plans to reanalyze the data for secondary purposes and, yet, you wish to keep the data indefinitely, please explain why.

SECTION G -- MONITORING ONGOING RESEARCH

It is the investigator's responsibility to notify the REB using the “Renewal/Project Completed” form, when the project is completed or if it is cancelled.
http://www.brocku.ca/researchservices/forms/index.php

24. Annual Review and Serious Adverse Events (SAE):

a) MINIMUM REVIEW REQUIRES THE RESEARCHER COMPLETE A "RENEWAL/PROJECT COMPLETED" FORM AT LEAST ANNUALLY.
Indicate whether any additional monitoring or review would be appropriate for this project.

No it would not be appropriate for this project.

*Serious adverse events (negative consequences or results affecting participants) must be reported to the Research Ethics Officer and the REB Chair, as soon as possible and, in any event, no more than 3 days subsequent to their occurrence.

25. COMMENTS

If you experience any problems or have any questions about the Ethics Review Process at Brock University, please feel free to contact the Research Ethics Office at (905) 688-5550 ext 3035, or reb@brocku.ca