"Where's the support?": An Exploratory Study of Supports for Primary Caregivers of Children with Autism Spectrum Disorder in the Toronto Region

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"Where's the support?": An Exploratory Study of Supports for Primary Caregivers of Children with Autism Spectrum Disorder in the Toronto Region

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THESIS
Submitted to the Faculty of Social Work
in partial fulfillment of the requirements for
Master of Social Work
Wilfrid Laurier University
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Abstract
The experience of being a caregiver of a child with Autism Spectrum Disorder (ASD) is complicated and fraught with obstacles. Presently, we do not know how to support caregivers adequately. In this thesis, I explore the supports that exist for primary caregivers of children with ASD in the Toronto region, with the goal of examining caregiver experience when accessing supports. The literature that I reviewed highlighted the importance of examining the caregiver experience by acknowledging that caregivers of children with ASD experience elevated levels of stress. This review made it clear that by not addressing how to support caregivers, the well-being of the caregiver and child are put at risk. More specifically, the efficacy of ASD treatment and intervention has been found to be compromised if caregivers are not provided with adequate support. The purpose of this study is to begin the conversation around what supports caregivers feel they need to alleviate the stress they feel from caring for their child. Five caregivers were invited to participate in this study. The study was informed using a social constructionist perspective, and semi-structured interviews regarding their experiences accessing supports in Toronto. A thematic analysis was used to analyze the data. Seven themes were identified through analysis: knowledge about ASD; the ability to listen; accessibility, care coordination/service navigation; waitlists; program structure; and need for work flexibility. Care coordination was the only theme that was mentioned by all five participants, which led me to conduct an in-depth examination of the issues surrounding this theme. Finally, an examination of how a community of practice model may be applied as an alternative form of support was explored, as are policy and practice implications and future research opportunities.
Acknowledgements

This thesis is dedicated to the children with ASD and those who support them.

I would like to thank my participants, as well as my committee members, who helped make this thesis possible.
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Chapter One: Introduction

Autism Spectrum Disorder (ASD) presents itself in individuals amidst a varying constellation of symptoms. Thus, the popular saying in the Autism community: “If you know one person with autism; you know one person with autism”. Over time, this individual variability has made providing diagnosis, treatment, and support of ASD a complex endeavour. Simply speaking, ASD is a neurodevelopmental disorder that affects an individual’s capacity to communicate and interact with others. In addition, varying degrees of behavioural difficulties often accompany the individual’s social impairment. ASD is labelled as a disorder within the Diagnostic and Statistical Manual (DSM), and therefore broadly recognized as one. However, it is not uncommon to be met with resistance when using the term “disorder” with respect to Autism, as many see Autism as an alternate way of experiencing the world. That being said, for the sake of research consistency, the DSM definition of ASD will be used, since it is the definition used in all previous research.

I was afforded a first-hand experience with the complexity of ASD through my employment with the Autism Treatment Network (ATN). The ATN is a North American network of researchers, hospitals and clinicians working together to improve care for children with Autism Spectrum Disorder (ASD). Due to this, I have been involved with children and families affected by autism in some capacity over the last three years. At first, my involvement was benign. It started simply as a research job, but quickly grew into a passion.

Finding empathy for the ASD community was not hard to do, as their struggles were through no fault of their own. Their obstacles they are subjected to are largely due to a genetic glitch and/or systemic issues. Over time, witnessing the lack of support for both the children with ASD and their families became a prime source of frustration for me. I could not understand
why there is so little for children with ASD and their families. I wanted to know why and do something about it.

An ideal form of support would involve a team of professionals’ providing aid to the individual. However, the reality is that most of the responsibility lies with primary caregivers. It’s become clear to me that in order to ensure the care of people with ASD, we need to ensure that their primary caregivers are adequately supported. It is important to have a basic understanding of the challenges of ASD if we are to start to get a sense of what the primary caregiver experience may be, and how we can support them in the way they need to be.

With that in mind, the purpose of this study is to identify the factors that lead to the best support system for primary caregivers of children with ASD in the city of Toronto. Undertaking this study is my way of directly trying to answer the question that many primary caregivers asked when I was working with them, namely “Where are the supports?” Specifically, this research allowed me to begin to examine the available resources/services to see if they are meeting the need that they claim to meet.

The Challenges of Autism Spectrum Disorder

Medically, Autism affects the way the brain functions, resulting in difficulties in the domains of socialization, communication, as well as unusual patterns of behavior, activities, and interests (Tschikof, 2012). The term “spectrum” is important to note because it indicates a continuum of severity of developmental impairment. All individuals with a diagnosis of ASD typically have certain communication, social, and behavioural characteristics in common. However, the conditions cover a wide spectrum, with individual differences in:

- Number and kinds of symptoms
- Severity: mild to severe
- Age of onset
- Levels of functioning
- Challenges with social interactions

As a result of ASD being a spectrum disorder, individual diagnoses vary. Depending on where an individual is on the spectrum, a person may manifest the following characteristics to varying degrees and in various combinations: difficulty with social skills, problems with communication, unusual responses to sensory stimuli, unique abilities, repeated behaviours and restricted interests, (Hughes-Lynch, 2012).

For caregivers of children with ASD, communication becomes one of the most problematic characteristics of ASD. It is not unusual for some to show minimal to no interest in other people while others may be interested but not know how to talk, play, or relate to others. Initiating and maintaining a conversation is typically challenging for individuals with ASD (Hughes-Lynch, 2012) and it is not unusual for them not to be able to interpret non-verbal communication, such as social distance cues, gestures, and facial cues (Autism Society Canada, 2015). These difficulties make it harder for caregivers to build bonds with their children at times, but even more difficult is watching their children struggle socially with their peers.

Outside of the communication difficulties, caregivers often have to contend with a range of behavioural difficulties as well. These difficulties include repeated ritualistic actions and restricted interests. For example, it is not unusual for a child with ASD to repeat the same action multiple times, or only be interested in playing with trains. Furthermore, it is common for an individual with ASD to have visual and auditory processing difficulties, these processing issues can range from mild to severe with over and under-sensitivities (Newschaffer, et al, 2006). The meltdowns that can occur in response to a change in the routine and/or a response to the external
sensitivities are often one of the hardest parts of being a caregiver of a child with ASD.

As much as caregivers can attempt to prevent their child from being triggered into having a meltdown, there is no way to control the environment or how other people may respond to their child. They know that their child is Autistic, but the public does not. For a caregiver, this is sometimes hard to reconcile, especially while their child is in the throes of a meltdown. In addition, the variability that exists within ASD makes treatment hard. There is no one-size-fit-all treatment. This makes it hard for professionals, but compounds the struggles caregivers may have when supporting their child. Most of the ASD programs and services are designed for those with an ASD diagnosis, however, it is necessary for supports for primary caregivers to be in place as well. It is important to acknowledge that though caregivers may love their child, it does not mean that it is easy for them to support them.

**Acknowledging the Primary Caregiver Experience**

The experiences of primary caregivers are not acknowledged within the health or service systems. If they were, the present structure would not require facilitation by professionals. As it stands, resources and supports require multiple referrals by doctors, therapists, and psychologists to legitimize the observations made by caregivers. Little thought has been put into those who need to navigate the system and how the experience may be difficult for them. The expectation is that individuals who need to access the system must learn to navigate this complex web. They are required to seek professionals or professional help, rather than having professionals seek out those who are in need. This is indicative of a society that places more emphasis on the knowledge of professionals than those who are going through the experience themselves.

Acknowledging that higher value is placed on the knowledge of professionals is important when addressing issues surrounding families who are affected by a disability. It means
that the system is set up with the professional in mind rather than the families who have to navigate the system to get the help they need. Anecdotal evidence shared by caregivers shows this as the large majority occupational and speech and language services require a referral from a doctor. It indicates that a visit with the doctor is worth more than the time a caregiver spends with their child every day. Whether the individual is the person with a disability or is supporting someone who lives with one, the expertise of the individual should be as valued as the expertise of professionals. With this in mind, it is important that when embarking on an exploratory study on primary caregiver resources/supports for children with ASD, that the participants are situated as the experts of their own experience. Keeping and honoring the experiences of primary caregivers was a central focus of the study.

Organization of Thesis

There are six main components to this thesis: introduction, literature review, study design, results, discussion, and the conclusion. Each component is an integral part of the picture and provides a different aspect of the story. The literature review provides an overview of what research has already been done on primary caregiver supports, offering a means to ensure that this study will not be redundant in the field. It begins with research around causes and prevalence of ASD, which though extensively done, has not come to any definite conclusions about the origination of ASD or why the numbers of diagnoses are rising. From there, research around the treatment of ASD is examined, the most popular form of treatment for those with ASD are forms of behavioural treatment. More specifically, applied behavioural analysis. The study design addresses the rationale, and steps behind the execution of the research. In the results, the themes and sub themes that resulted from the analysis are outlined and discussed in detail. In the discussion, the thematic findings are explored as they relate to existing literature. Within the
In conclusion, this study’s findings on the field of autism and areas of future research will be discussed. In addition, my reflections on the research process as well as a brief overview of how my perspective has changed from undertaking this research will be looked at. By the end, it is my hope that a reader would start to understand not only that more support is needed for primary caregivers, but why it is needed.
Chapter Two: Literature Review

Due to autism being a spectrum disorder, it has great individual variability (Dyches, Smith, Korth, Roper & Mandleco, 2012). However, despite the variability, this disorder has consistent hallmarks involving altered function in socialization and communication (Tshcikof, 2012). In addition, Tshcikf (2012) also notes that unusual patterns of behaviour, activities, and interests are common among those with a diagnosis of ASD. The severity of the symptoms inform whether the diagnosis of ASD is categorized as high functioning or low functioning. Due to the variability and complexity, the scope of the research done on and around ASD is incredibly large and encompasses a number of disciplines from behavioural intervention to neurophysiology.

The literature review contextualizes the primary caregiver experience, beginning with an examination of ASD. It includes proposed causes, prevalence, and current interventions. Thereafter, it focuses on literature regarding the role and experience of caregivers, and caregiver support.

Causes and Prevalence of ASD

When it comes to determining a cause of ASD, the field that has made the greatest gains towards finding an answer is genetics. Genetic explanations for ASD are constantly evolving, with the biggest discovery thus far being that the genetic risk for autism resides within common genetic variations (Gaugler & et al, 2014). Other areas of investigation include exploring gene-environment interactions, which examines how environmental factors may affect genotype expression (Manuck & McCaffery, 2014). Direct evidence of this comes from studies that look at how prenatal and perinatal factors and drugs and toxic exposure affect ASD diagnoses (Chase & Leboyer, 2012). Alternate avenues of genetic research involve investigating why rates of ASD
continue to be higher in males than females (Verma, et al., 2014), with the sex ratio being biased towards males at a rate of four to one (Newschaffer, et al., 2006). This means for every four males that are diagnosed with ASD, one female is diagnosed. Despite advancements in research, there is no conclusive evidence that indicates a single cause for ASD.

 Genetic research is also looking into why the rate of autism diagnosis for children has been steadily increasing over the past two decades to reach the current prevalence of 1 in 68 people (Autism Speaks, 2014). As it stands, genetic research has not been able to provide concrete reasons for why there has been an increase in the rate of autism diagnoses, just that there has been an increase. However, other research has suggested that an increase in the prevalence of ASD may be due to the increasingly sensitive diagnostic tools (Zylstra, Prater, Walthour & Aponte, 2014). Zylstra et al. (2014) highlights that there is a direct relationship between the development of better diagnostic tools and the rise of ASD diagnosis. The suggestion being that ASD rates may not have increased, but with better developed diagnostic tools and criteria, fewer individuals are being missed.

 For this study, the genetic root of ASD is not as relevant as the fact that all the evidence shows that the rate of ASD is rising. In fact, for social work it does not really matter how or why the rate of ASD is rising, just that it is. Agencies and centres that provide programs and services for this population need to be aware of the influx of the population in order to be prepared to support them.

**Intervention of ASD**

 The improvements made in diagnosis also mean that the identification of symptoms has become more nuanced, which has had a direct effect on the development of treatment and intervention options. An additional benefit of sensitive diagnostic tools is that a diagnosis of
ASD can be given earlier. It is now common for ASD diagnoses to occur before the age of two (Itzchak & Zachor, 2011). Early diagnosis is beneficial as intervention research has found overwhelming evidence that early intervention provides the best probability of a child making the most developmental gains in language, social, and emotional realms (Rogers et al., 2014). Furthermore, regardless of the intervention and treatment option that the child may be involved in, earlier interventions are correlated with improved outcomes (Itzchak & Zachor, 2011).

As previously stated, a hallmark of ASD is the variability of symptoms between individuals. Therefore, it is not a leap to imagine that the intervention and treatment options are also incredibly variable. In a study conducted by Green et al. (2006) more than a hundred treatments for ASD were identified with the most commonly reported interventions falling under two categories: educational and therapeutic. Applied behavioural analysis (ABA) fell under the category of educational intervention, while the most common therapeutic interventions were speech and language (SLP), occupational therapy (OT), and physical therapy (PT). The multitude of interventions available was corroborated by a meta-analysis done by Markygianne and Reed (2010).

Despite the number of interventions that exist, there has been little evidence provided for the effectiveness of interventions that are not educational, more specifically, the most studied approach is ABA (Markygianne & Reed, 2010). According to Maurice, Green & Foxx (2001) there are several models of ABA intervention, but all of them should have the following set of seven core features: (1) treatment may begin as early as 3-4 years of age, (2) intervention is intensive (20-40 hours a week) and requires additional teaching and practice goals to be maintained during most waking hours, (3) intervention is individualized and comprehensive targeting a wide range of skills, (4) multiple behavioural analytic procedures are used to develop
adaptive repertoires, (5) treatment goals are guided by normal developmental sequence, (6) treatment starts on an individual basis and transitions to a group setting, (7) and to varying extents, parents are trained and become co-therapists.

The popularity of ABA is grounded in the positive results that are reported within the realms of daily living skills, academic performance, and communication skills (Eikeseth, Smith, Jahr & Eldevik, 2007). In addition, studies have suggested that children who undergo ABA intervention have a greater chance of integrating into school without additional specialist support (Virues-Ortega, 2010). Other studies comparing ABA to other interventions have provided mixed evidence supporting Virues-Ortega’s (2010) claim. For example, comparing ABA to an intervention known as the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) provides evidence that favours ABA (Virues-Ortega, Julio, Pastor-Barriuso, 2013). In fact, a meta-analyses done by Eldevik et al. (2009) not only confirms this finding but provides evidence that TEACCH does not compare favourably to any other approach. However, Pivotal Response Therapy (PRT) has shown to be more effective than ABA at improving social communication skills, and prosocial behaviour, and skills had a higher chance of becoming generalized (Mohammazehri, Koegel, Rezaee & Rafiee, 2014).

The effectiveness of PRT may be the reason why PRT has grown in popularity in recent years. PRT is built on ABA principles but addresses the shortfalls of ABA intervention. As effective as ABA is in producing behavioural changes, there are areas of difficulties: gains are extremely slow, gains that occur do not always generalize, and children are not typically motivated to be involved in the teaching sessions (Koegel et al, 1998). By focusing on variables known to improve responsiveness, rate of responding and positive affect, and including child choice, PRT is able to make gains where ABA cannot (Mohammazehri, Koegel, Rezaee & Rafiee, 2014).
Despite the popularity of behaviour interventions and the fact that parent involvement is listed as a core component of interventions such as ABA (Maurice, Green & Foxx, 2001), robust research has not been done on the relationship between interventions and their impact on parents. Rather, the research revolves around whether parents are able to maintain the parent training outside of the clinical setting with evidence suggesting that it is not easy for parents to do so (Patterson, Smith & Mirenda, 2011). A meta-analysis done by Markyianne and Reed (2010) suggests that despite programs requiring parental involvement, only half provided the relevant training. This suggests that professionals facilitating interventions do not value parent involvement. It is important for parents to understand and know how to use the behavioural techniques because they contribute and enhance the learning environment for a child by providing consistency and continuity (Patterson, et al., 2011).

There are a number of interventions available for children with ASD, and on average, children with ASD receive seven interventions at any given time (Green et al, 2007). Within therapeutic interventions, SLP was found to be accessed the most due to the communication deficits that are common among those with ASD (Patten, Baranek, Watson & Schultz, 2012). OT and PT services are also popularly utilized as they target issues that may occur in daily living and school performance, which include problems around sensory issues, as well as fine-motor and/or play skills (Hodgetts & Hodgetts, 2007). Other common therapeutic interventions involve pharmaceuticals or alternative medicine: it was found that 40% of children under the age of 8 receive a form of medication (Thomas, Ells, McLaurin, Daniels & Morrissey, 2007). Green et al. (2006), indicate that sleep aids, anti-psychotic medication, and antidepressants are used commonly among children with ASD. While alternate interventions typically involve vitamin supplements or dietary changes such as gluten- or casein-free diets (Patterson et al., 2011).
The majority of research around intervention focuses on efficacy and improving interventions. As it stands, behavioural interventions set standards for parents to meet within the home with little thought to how sustainable they are. Time is a luxury for parents if we consider how the above literature suggests a child is likely accessing SLP, OT, PT, as well as a form of alternate intervention at any given time. The role of parents is an important one for any child, but for a child who has ASD, it becomes much more important. By focusing a study around primary caregiver supports, it acknowledges the competing priorities that parents may have and that they need to be able to access day-to-day support if needed.

**Role and Experience of Caregivers**

The role of caregivers has been explored widely in geriatric, development, health, and disability literature. With respect to caring for an individual with special needs, the role of caregivers is typically investigated in relation to caregiver burden. It has been unanimously acknowledged across all fields that caregivers of individuals with complex and long-term needs experience “caregiver burden.” George and Gwyther (1986) define caregiver burden as the combination of physical, psychological, emotional, social, and financial stress that individuals experience as a consequence of providing care. It has been suggested that the concept of caregiver burden has been a useful way to conceive of how the caregiving role may be negatively impacting those who take it on (Bastawrous, 2013).

Research on caregiver burden attempts to pinpoint the causes, effects, and ways to alleviate the weight of responsibility that caregivers may feel. Causes of caregiver burden for those who parent a child with a disability have been shown to fall under two categories. The first is the individual burden that a caregiver may feel from providing direct assistance in day-to-day activities and adjustment issues and the second category is external factors (Bourke-Taylor,
Howie & Law, 2010). Some of the external factors noted in the literature are: navigating poorly coordinated and non-responsive service systems and dealing with the societal rejection and social stigma that comes with having a child with a disability (Green, 2007).

There is overwhelming evidence that caring for a child with a disability has inevitable consequences for caregivers’ time and resources (Green, 2007). This stress comes from the additional responsibilities and needs the child may have. It has been shown within disability research that caregivers of children with ASD are especially prone to caregiver burnout as they experience higher levels of stress than those who have children with other disabilities (Davis & Carter, 2008). The nature of ASD may be largely responsible for the elevated stress levels that these caregivers feel. Mao (2012) discusses how parenting a child with ASD involves additional stressors related to the child’s challenges around communication, unpredictable behaviours, and limitations in self-care. She goes on to further discuss the social isolation parents may feel because of the lack of respite, which is due to the inability of finding a suitable substitute caregiver (Mao, 2012).

Autism research has begun to empirically acknowledge that primary caregivers of individuals living with ASD experience higher levels of parenting stress. Such stress has considerable consequences for caregiver and the child (Osborne, McHugh, Saunders, & Reed, 2008). As stated by Estes et al. (2013) “parenting stress” is defined as stress that is directly tied to the parenting role and should be distinguished from “psychological distress” (pg. 137) since the latter is reflective of a more stable trait. Research around parenting stress has not only looked to examine levels of stress experienced by the primary caregivers of individuals with autism, but also the causes and consequences of such stress.
Higher parental stress has consistently been associated with higher levels of ASD symptoms (Davis & Carter, 2008). This is understandable as the symptoms of ASD can be hard to manage not only due to the severity, but also due to the variability that can exist in any given individual with ASD. The stress of managing the behaviour, psycho-social, developmental, and regulatory challenges that come with ASD is overwhelming (Davis & Carter, 2008; Carter, Irwin, Skuban, Davis, & Briggs-Gowan, 2005). In particular, child behaviour challenges have shown to heighten parental stress, even more than the child’s developmental delay (Baker, et al, 2003). In fact, behavioural problems are the most important predictor of caregiver psychological well-being (King, et al, 1999). Examples of common behavioural challenges seen in children with ASD range from defiance and escape behaviours to aggression and property destruction (Sikora, et al, 2013).

After behavioural challenges, the psycho-social challenges that come with ASD have been shown to cause high degrees of parenting stress and psychological distress (Estes et al., 2009). The research suggests that because ASD impairs social relatedness, it becomes emotionally painful for caregivers (Estes et al., 2009). Caregivers are required to learn a new way of relating to their child, and it requires time to adapt to and accept such changes. It is not surprising that caregivers find this distressing. Outside of symptom severity, there is also a relationship between parenting stress and age of the individual with ASD (Phelps, McCammon, Wuensch, & Golden, 2009). That is, the younger the individual with ASD, the higher the levels of parenting stress (Phelps et al., 2009).

Outside of stressors that are specific to caring for a child with ASD, balancing work and family needs has shown to be extremely stressful for caregivers (Matthews, Booth, Taylor, & Martin, 2011). Work-family literature has shown that coordinating work and caring
Responsibilities can be extremely demanding, when it comes to time, energy and commitment, and has the possibility of affecting their employment (George, Vickers, Wilkes, & Barton, 2008). For caregivers who are working, workplace flexibility constituted to be one of the most significant issues they faced (Matthews, et al, 2011). Working primary caregivers are forced to modify their working arrangements by working part-time, rearranging working schedules, taking time off, and for some, stopping work altogether to meet the needs of the child (Leiter, Krauss, Anderson, & Wells, 2004).

Evidently caring for an individual with ASD is related to high levels of parental stress and in turn parental stress has been linked to caregiver burnout. Elevated stress levels are more likely to occur when caregivers are also required to juggle both employment and caregiving duties. “Caregiver burnout” is defined as a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude (Palmer, 2013). The concept of caregiver burnout is not explicitly researched in the field of autism, but is noted through research that identifies how physical and mental health of primary caregivers of individuals with ASD are affected (Carter et al, 2009). In fact, it is common for caregivers to report experiencing symptoms of depression and anxiety (Estes, et al., 2013). Furthermore, these mental and physical effects of rearing a child with ASD have been shown to manifest themselves in fatigue (Giallo, Wood, Jellett, & Porter, 2011). Giallo et al. (2011) examined the relationship between fatigue and wellbeing and conceptualized fatigue as an outcome of health and wellbeing. In congruence with similar studies, it was found that fatigue is a serious issue that can impact parents’ daily functioning and in some cases their ability to care for their children (2011).

Such findings mean that parental stress affects both the caregiver and the family’s quality of life (Lloyd & Hastings, 2008). The research done around the function of families with a child
who has ASD is not extensive, but what research has been done indicates that poor parental mental health negatively affects family function (Johnson, Frenn, Feetham, & Simpson, 2011). Typically, family function is defined as a commitment by family members to support the functioning of a family, which includes economic security, safety, child-rearing, caregiving, and communication (Johnson, et al, 2011). Preliminary research has even shown that among families with high parental stress, family functioning is at times compromised to the point of family crisis (Weiss & Lunsky, 2011).

These findings are in line with another notable consequence of parental stress that professionals should keep in mind: the effectiveness of interventions for children decrease when parental stress is high (Osborne, McHugh, Saunders, & Reed, 2008). This is an important finding for professionals who are involved with intervention programs for individuals with ASD to keep in mind. This finding is made even more significant when connected to research that has shown that higher levels of behavioural symptoms contribute to parental stress (Sikora, et al., 2013). These findings suggest a cyclical relationship between increased parental stress, decreased intervention effectiveness and increased behavioural symptoms. It is necessary for the cycle between parental stress and ASD symptomatology to be broken in order to improve the quality of life for the family members involved. It is important to understand what supports are effective and needed for caregivers in order to intervene and disrupt this cycle. This study looks to address this issue and add to the conversation of what caregivers feel they need to feel supported.

**Caregiver Supports**

Research has shown that stress levels are lower for primary caregivers who are provided with support (Johnson, Frenn, Feetham, & Simpson, 2011). Traditionally, supports have been studied under two main categories: informal and formal (Marshak, Seligman, & Prezant, 1999).
Informal supports are networks made up of family and friends, while formal supports refers to accessible professionals (Zablotsky, 2013).

It has been found that informal supports are effective in reducing parental stress, however, for primary caregivers of children with ASD, a subset of informal supports have been found to be the most effective (Gualnick & Hammond, 2008). Guralnice and Hammond (2008) have shown that “parental support” is helpful in reducing parental stress. Parental supports refer to support from other parents who are going through a similar experience (Meirsschaut & Warren, 2010). For the case of primary caregivers with children with ASD, parental support refers to obtaining support from other primary caregivers with children with ASD. Though the importance of family and friends providing emotional and relational support to primary caregivers should not be discounted, such supports are not as effective in reducing parental stress (Zablotsky, 2013).

Whitaker (2002) defined these two types of supports as “general support” meaning emotional support, and “parenting support” meaning providing parents with practical advice and strategies specific to their child. Thus, when looking at supports for primary caregiver of children with ASD, it is necessary to differentiate between types of support to properly explore whether an appropriate support system exists. This particular point was kept in mind when designing the present study, the hope being that this study will be able to not only address whether support exists for caregivers, but also the kind of supports available.

Research on primary caregivers consistently points to the fact that parents want support that will help “make sense” of their child. This finding means that when developing support programs for primary caregivers of individuals with ASD, it is necessary to make sure that the knowledge and skills they learn within the program can be transferred to their daily life. These
outcomes are useful for primary caregivers who are able to access services. However, for many families who have children with ASD, they not only have difficulty accessing services and programs, but they cannot find information that is relevant to them (Murray, Ackerman-Spain, Williams, & Ryley, 2011). These primary caregivers also report poor collaboration between organizations working with their children and a lack of continuity between supports, which compounds parental stress (Haney, 2011).

**Research Gaps**

ASD is a complex matter as proven through the literature. The cause of ASD is ultimately unknown, yet the prevalence of ASD is rising. A natural consequence of a growing ASD population is that there will be more caregivers. Researching on the experience of caregivers of children with ASD is slowly gaining momentum, but the field seems to place far more focus on the individual with ASD than those who support them.

The goal of the field of autism and the caregivers is essentially the same, to better the lives of those who live with ASD. However, not enough thought is spent on how to support caregivers in this pursuit. Instead, treatments that are proposed by professionals require an enormous amount of time to ensure consistency and continuity on the part of caregivers and little is known on how caregivers may mediate treatment effectiveness. Research has shown that maintaining the same standard of care that the child may have had in a clinical setting is not feasible for caregivers. Yet, the field continues to support forms of behavioural therapy as the gold standard of ASD care without looking at how to support caregivers in maintaining the gains that the child may make in therapy (Moore & Symons, 2011). The connection between caregiver support and treatment efficacy has only been touched on and needs be investigated more thoroughly.
The competing priorities that caregivers have on their time have been shown to cause individual stress. The ramifications of parental stress do not only affect the physical and mental wellbeing of the primary caregiver, but also the entire family unit. Evidence has begun to show that high levels of parental stress also interfere with the interventions that may be in place for the individual with ASD. Thus, the cycle of family stress and ASD symptomatology is perpetuated. Parental supports have been shown to alleviate parental stress. Such supports are specific to providing assistance in parenting a child with ASD, and this can come in the form of advice or respite care.

Ultimately, the literature shows that caregivers are an integral form of support for children with ASD. Although, it is important to highlight that caregivers undergo an immense amount of stress to provide the support needed by a child with ASD; and they too require support in their day-to-day life in order to maintain their quality of life. Though research indicates caregiver support is important for the wellbeing of the individual and family, none of the research contextualizes or acknowledges that support systems are affected by regional differences. The literature states that supports delivered by professionals are necessary but does not seem to recognize that service systems vastly differ between communities. It is important to geographically contextualize these findings, as each community has a different support network. What may work for rural caregivers may not work for those who live in an urban setting.

This being said, there has yet to be a study that looks at the support network within the city of Toronto. It is important to know what supports primary caregivers are accessing and what they find useful in alleviating parental stress in order to move towards creating a network that meets their needs (Murray et al., 2011). With this in mind, the need to explore what is needed to create a supportive system for primary caregivers of individuals with ASD is important.
Chapter Three: Methodology

My study is designed to answer the main research question: what is needed to create a supportive system for primary caregivers of individuals with ASD in the Toronto region? With this in mind, I thought it was natural for this study to be qualitative. A hallmark of qualitative work is to gather in-depth understanding of human experience and to identify the interplay of the variables that may affect it (Crouch & McKenzie, 2006). The essence of qualitative research aligns well with the two main tenets that I kept in mind when designing this study. Firstly, this study is exploratory, and secondly, I believe it should represent the primary caregiver’s experience. It was essential that the paradigm and theoretical framework chosen for my study could represent the individuality of the participants may have, while leaving flexibility for the feelings of community that caregivers develop in support networks. Being cognizant of this, the paradigm selected was social constructionist, while the framework was community of practice

Paradigm and Theoretical Framework

A social constructionist approach will be the underlying paradigm used in this study as it values the individuality of experience. Operating under this paradigm requires the research to look at the complexity of views rather than generalized narrow meanings (Creswell, 2007). The goal of such research is to rely on the participants’ view of the situation and how they experience it. It is important to situate the participant as the expert of their own experience and not constrain their accounts by rigid measures. Furthermore, it is also important to acknowledge that the experience that participants’ presented is affected by virtue of the fact that they are knowingly discussing their experiences of supports with a researcher. The socio-cultural complexity of each primary caregiver experience when accessing supports for their child with ASD differs between
individuals. Such nuances can be illustrated under a social constructionist paradigm and it’s relating theories.

A social theory that overlaps with social constructionist approach is community of practice. The formal definition of “community of practice” is a collection of people bound together by location, purpose, activity, values, desires, and perhaps labels (Lave & Wenger, 1991). Though the use of this theory has been popular in a number of fields, the popularity is only just starting to grow within disability research as the applicability becomes more apparent (Lawthom, 2012). The appeal of communities of practice for disability research lies in the fact that this theory situates otherwise marginalized individuals as experts in their own right. Even more important is the fact that communities of practice hold the knowledge from such communities as equally valuable to professionals. At its core, communities of practice share the same elements of strong support networks (Lawthom, 2012).

The fit between social constructionism and communities of practice lies in the fact that both believe that understanding, significance, and meaning are developed in relation to other beings. However, they respect that individual recollection of experience may differ based on each individual’s perception of their experience. Thus, both lend themselves to qualitative research and more specifically, interviews of participants. The role of the communities of practice framework and the underlying currents of social constructionist view will become more apparent in the thematic analyses of the interviews and the subsequent report.
**Research Questions**

Primary questions: What supports are there for primary caregivers within the Toronto region?

What is the experience of them?

Secondary questions:

- Do the roles of informal and formal supports differ? If so, how?
- What formal supports/services/programs are being accessed?
- Which support(s) alleviated the most caregiver stress?
- What do caregivers feel they need in terms of support?

**Research Design**

For this study, I chose to focus on exploring the experiences of primary caregivers of children with ASD in accessing supports, resources, and services. Thematic analysis is the best design to highlight the ever-evolving needs and the changing supports accessed by a primary caregiver, family, or child with ASD. Utilizing an analysis that is able to provide a rich and detailed account of the experience of being a primary caregiver from the point their child is diagnosed to present was necessary in order to accurately speak to the supports that are present or should be present within the Toronto region.

As this is an exploratory study, generalizability of results was not a key objective. What is more important is to ensure that the experiences of the primary caregivers are accurately represented and appreciated as unique to them. By engaging in a thematic analysis, I am able to both appreciate and critically analyze the uniqueness of each participant. The beauty of thematic analysis is that though the crux of the analysis is to find patterns of meaning across all participants, the onus is on the researcher to analyze the interviews consistently and rigorously and not for the participant to say the “right” thing (Attride-Stirling, 2001).
In a similar vein as other qualitative research techniques, a thematic analysis will allow the primary caregiver to represent their experiences and stories how they choose, which is a hallmark of any disability research (Goodley, 2013). Appreciation of the individual experience remained at the forefront of the research when embarking on the thematic analysis of each participant’s journey. It was important to consider the experiences of the primary caregivers especially when attempting to explore a complex system such as primary caregiver supports. Furthermore, such contextualization of experience facilitates the thematic analysis and leads to a clearer abstraction of relevant themes.

**Invitation of Participants**

The population of interest is primary caregivers of children with Autism Spectrum Disorder (ASD) that reside within the Toronto region. Recognizing that this is a broad population, I defined what “primary caregiver” and “children with ASD” meant for this study. I decided that “primary caregiver” would mean the mother of the child, while “children with ASD” was understood as a child who has received a diagnosis of ASD and is between the ages of 4 to 10 years. Mothers were chosen as they are the most likely to take on the primary caregiver role, and because previous research also has used mothers as their representative population. With respect to the age range, I selected it to ensure a low likelihood of the child being pubescent, since puberty has complicated effects on children with ASD. Furthermore, I wanted the children to be school-aged, since families often access supports through the school system. With respect to the geographical region, I defined “Toronto” to encompass the area south of the 401 highway to Lake Ontario, as well as the area from Keele to Coxwell. Lastly, all participants had to be fluent in English due to my own language limitations.
I acknowledge that due to the nature of ASD, a diagnosis of autism is still considered quite broad. However, the DSM-V has moved towards a general diagnosis of ASD, and it is important for the study to remain consistent with such diagnostic changes. Limiting participation based on autism severity would unnecessarily exclude individuals from participation who have received a general ASD diagnosis. In sum, I invited five primary caregivers to participate, each of which had a child with ASD between the ages of 4 to 10 years that reside in the Toronto region. I intentionally invited a small number of participants as the study is designed to be exploratory. In fact, a small sample size has shown to be advantageous in exploratory studies as it allows the interview process and analysis to be more thorough (Crouch & McKenzie, 2006).

Due to the specificity of my participant invitation criteria, I used purposive representation, which is defined to be recruiting participants directly from the target population (Creswell, 2007). More specifically, the form of purposeful representation that was utilized would be categorized under criterion representation. Criterion representation is a form of purposeful representation that uses specific criteria to ensure that the participants will meet the study conditions (Sandelowski, 2000).

I did this by focusing recruitment through the Autism Treatment Network, which is situated within Surrey Place Centre, an organization that caters to children and families with ASD in the city of Toronto. I made further specifications by outlining the recruitment criteria, which required participants to be English-speaking, living in the Toronto area, and a caregiver of a child with ASD who was between the ages of 4 to 10. A staff member within the Autism Treatment Network and Surrey Place Centre assisted me in gaining permission to circulate my recruitment materials. Advertising the study involved circulating the research flyer in the form of an e-mail blast using a parent listserv. If parents were interested in taking part in the study, they
contacted me via an email address I provided on the research flyer. In order for recruitment to take place via the organization, the research study was required to go through Surrey Place Centre’s (SPC) research ethics board.

Before submitting the research study to ethics I was required to complete the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics*. My research was required to go through both Wilfrid Laurier and SPC’s research ethics boards before I could commence my recruitment. In both cases, the ethics board deemed my study acceptable as long as I implemented check-ins with the participant to ensure that they were not feeling overwhelmed by the interview process.

**Research Location**

This thesis is situated in Toronto, Ontario, more specifically, in the downtown core. Toronto is Canada’s largest city, the fourth largest in North America, with a population of approximately 2.8 million people (City of Toronto, 2015). Statistics Canada (2011) identified 1,529,235 families, with 70% of them stating that they have children living at home. 18% of families identified as being lone-parent families. The median income for families in Toronto in 2011 according to Statistics Canada was $69,740, while the lone-parent median income was $39,590.

With respect to developmental services there is no catalogue of how many centres offer ASD specific services and where they are located. This is part of the problem that primary caregivers face. Furthermore, there are no exact numbers of how many people in Toronto live with ASD, but there is no doubt that within the city of Toronto the number of children with ASD outnumbers the services and programs available.
Sample Profile

All five participants that were invited to participate were mothers of children with ASD. Their ages ranged from 35 to 42 years of age. Two participants reported being married, one reported being separated, and the remaining two stated that she was single. The minimum education level was at a high school level, with four participants obtaining a university education. Of the four participants, three had attended graduate school. Three participants reported being employed, with one of the three being self-employed. The ethnicities that participants self-identified with were all different: Caucasian, Black, Portuguese, Argentinian, and Asian.

As this is a study of primary caregivers of children with ASD it is important to obtain demographic information about the family as well. Of the five participants, two reported having only one child, two reported having two children, and the remaining participant reported having four children. All participants only had one child with ASD. The age of the children ranged from 2 years old to 9 years old, while the range of diagnosis age ranged from 2 to 6 years old. The average age of diagnosis was 3 years of age. Of the five children, three were reported to be attending school.

Data Generation Procedures

The primary means of data generation was to interview the participants. The interview was semi-structured, providing enough guidance to ensure that the questions are answered, yet not too much that the participant was constrained by the questions asked. This allowed new ideas to be brought up during the interview in reaction to what the response may have been. I recorded each interview using a digital recorder. I interviewed each participant in an assessment room within Surrey Place Centre, and ranged from 45 to 60 minutes long. Depending on the
participant, I was required to ask more questions in order to obtain the information needed. Regardless, I found it a privilege to conduct the interviews and be privy to their personal experiences. Upon recording the interview, I transcribed it for later analysis. To supplement the interview, I required each participant to fill out a brief demographic survey.

**Data Recording Procedures**

To ensure confidentiality, I assigned all participants participant numbers and aliases. The list that contained contact information and the corresponding participant number was password protected and saved on a secure storage drive. Though I recorded the interviews via voice recorder, I followed an interview protocol to ensure consistency, as well as a means to record points that should be highlighted during the transcription. The transcription involved me listening to the interview audio files on a computer and manually typing out the interview using a word processing program. I anonymized the interview protocols I used and the brief demographic surveys that the participants filled out, filed according to participant number, and stored in a locked filing cabinet. Participants were not given honorariums, and participated in this study from pure interest.

**Data Analysis Procedures**

For the purposes of this study, the analytical approach that was most appropriate was thematic. Thematic analysis allows for the discussion of experiences to be focused around common patterns, processes, and features in the participant’s lives with respect to primary caregiver supports. By drawing together commonalities, unique experiences also become more apparent. Braun & Clarke (2006) succinctly outline a clear process for thematic analysis:
| **Familiarizing with data** | • Transcribing data, reading and rereading the data  
|                           | • Making notes of the initial ideas  |
| **Generating initial codes** | • Coding features of the data systematically across the entire data set  
|                           | • Collating the data relevant to each code |
| **Searching for themes**    | • Collating codes into potential themes, and gathering all the relevant corresponding data |
| **Reviewing themes**        | • Checking if the themes work in relation to the coded extracts and the entire data set |
| **Defining and naming themes** | • Ongoing analysis for refining the specifics of each theme and the overall story that the analysis tells  
|                           | • Generating clear definitions and names for each theme |

I read the transcripts several times and responses and organized them chronologically. Through this process, two main themes emerged, namely *micro* and *macro*. Each participant response was coded according to these themes. Upon concluding the initial coding, the micro and macro data were separated and analyzed in detail. The sub themes that developed under the micro theme were *knowledge about ASD* and the *ability to listen*. There were five sub themes within the larger macro theme, which were: *need for work flexibility, program structure, waitlists, care coordination/service navigation*, and *accessibility*. The sub themes were based on the following terms/concepts:
<table>
<thead>
<tr>
<th><strong>Micro</strong></th>
<th><strong>Macro</strong></th>
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| Knowledge about ASD | • Friends/family with children with ASD  
• Professionals with expertise in ASD  
• Personal experience with ASD  
• Advice about ASD |
| Ability to listen | • Listen  
• Support/supportive |
| **Accessibility** | • Obstacles to access  
  o Language  
  o Physical  
  o Cultural |
| Care coordination/Service navigation | • Services  
• Coordination  
• Navigation  
• System |
| Waitlists | • Waitlist  
• Waiting |
| Program structure | • Groups  
• Time  
• Programs |
| Need for work flexibility | • Employment  
• Work |

Upon establishing the relevant sub themes, I developed a description based on all the points that were mentioned by the participants. I selected quotes and excerpts from the four participants that provided consent to be quoted in the study and that best represented the overall description of each sub theme.
Trustworthiness

I used three techniques in order to ensure that the information that I would be presenting is credible and a fair representation of the participant experience. These techniques were, member checks, progressive subjectivity checks, and peer debriefing (Lietz, Langer & Furman, 2006). After transcribing the participant interviews, I sent them to each participant to be member checked. This allowed the participants to review for accuracy and comfort at their own pace. If necessary, at this time they also had the opportunity to correct anything that they had said during the interview. I did not move forward with the analysis until I received confirmation that the participants felt that the raw data was a fair representation of the interview that occurred.

Progressive subjectivity checks occurred throughout the research process. For instance, during the interviews I had to make sure that I was not biasing the findings by asking the participants leading questions. I was especially cognizant of checking during the analysis stage as it became apparent that the findings that I thought I would have were not going to be the main findings of the study. I remained aware of my evolving expectations by noting them down as they came up. By doing this, it allowed me to identify how my expectations could be colouring the research.

Peer debriefing occurred by regularly discussing my research process and evolving findings with my peers. They were able to offer valuable perspectives and inconsistencies that I may not have originally seen. Admittedly, my peer debriefing did not occur as rigorously as I hoped, due to the time constraints of my peers. Ideally, I would like to have had this research to occur within a team, where each team member works on a different project but can easily facilitate dialogue about process, analysis, and findings. Working in a larger environment would have also allowed findings to be ascertained by multiple inquirers. Ideally, I would have had at
least one other person read the transcripts and go through the analysis process. Comparing findings from the separate analyses would have made the research richer, however, due to the nature of the study and ethics approval, only I was able to read the participant interviews.

**Ethical Issues**

As with any study, especially one that involves human participants, there are ethical issues to consider. The main ethical issue that I needed to consider was that in order to discuss the supports that primary caregivers felt they needed, they had to reflect on a time that could have potentially been very hard for them. The process of diagnosis and receiving a child’s diagnosis of ASD can be traumatizing for a parent. It is something that I had to be aware of as a researcher and ensure that I did not cause undue distress. Outside of being sensitive and empathetic with the experiences that participants were sharing with me, I had to be aware of confidentiality. As with any diagnosis, the knowledge that a participant has a child with ASD must remain private. There could be both personal and social consequences of breaking such confidentiality. Having a child with diagnosis of ASD could be stigmatizing in some families or cultures and sharing that knowledge could cause emotional and social stress for the participant.
Chapter Four: Findings

I asked participants about their experience of services and supports beginning from the point of diagnostic assessment to services and supports presently used; these included any number of behavioural or therapeutic services. During the interview, I broadly asked participants about their formal and informal supports, and whether they felt that their “parenting stress” was lowered due to their access of these supports. As expected, the responses for all five participants were unique as a result of being based on their individual circumstances as well as the uniqueness of their child with ASD. Beyond the individuality of experience of each participant, several themes emerged upon analysis.

I anticipated that the findings from primary caregivers would highlight the elements that make a support or service particularly beneficial or helpful in reducing their parental stress. However, the findings showed that though I asked participants about supports and services, participants were more inclined to discuss why they thought the available supports and services were failing them. What came about were many systematic themes that illustrated a very potent primary caregiver experience of accessing services and supports for both themselves and their child. For that reason, I structured the organization of the thematic analysis broadly under two categories: “Micro themes of support” and “Macro themes of support”.

The themes that fall under the micro category address the different elements that have made caregivers feel supported when accessing services and supports. I defined the micro category as elements of support that can be provided by individuals. Whether they were friends, family, or professionals helping with the care of their child, these individuals involvement did not necessitate delivery of care through an organization or group. The macro category involves
themes that I extracted from the participant’s commentary on the system and the systemic issues that they felt were holding back from supporting individuals with ASD and their families.

**Micro Themes of Support**

Regardless of whether the participant discussed feeling supported during the diagnosis process or being supported from friends and family, two key elements were always mentioned: knowledge about ASD and the ability to listen. Although both elements are important for a participant to feel supported, based on the findings, an inverse relationship was established. Depending on whether the individual supporting the participant was a professional or a family/friend, the participant was more likely to place an emphasis on one element of support over the other. More specifically, participants emphasized a professional’s knowledge of ASD over their ability to listen, and vice versa with respect to their family and friends. However, professionals and friends who possessed both elements received special mention by all participants.

**Knowledge about ASD**

Amelia:

…I was lucky that when I received my son’s diagnosis I work with two people and we are actually a very close-knit group and two of my colleagues have kids on the spectrum. So when I received my son’s diagnosis one of the first things I did was call my colleague who has two kids on the spectrum and we talked about it and he was very supportive. My friends have been very good and they ask me a lot of questions. People have made all kinds of assumptions and they all ask how to act which is sometimes annoying…

…Speaking to those who have kids on the spectrum tends to be simpler. Everyone has good intentions. My friends are fantastic…
Teresa:

…Other people try to tell you what to do but you can tell that they are thinking “I don’t know what it is like to be in your position”. It is the ones that have to go home and have to deal with it (a child with ASD) that you want to hear from…

Participants felt most supported by professionals when they felt that they had knowledge about ASD and could assist with helping them understand what their child may need. This was especially important to participants at two different stages: in the beginning prior to receiving a diagnosis, and upon receiving the diagnosis of ASD. It is the most important at these stages for professionals supporting them to possess knowledge about ASD in order to help the caregiver make sense of their child. Most participants stated that receiving the diagnosis was overwhelming for them, even for those who had suspicions that their child may be on the spectrum. They look to the professional to make sense of the diagnosis and for what their next steps may be. Those participants who received a diagnosis from a professional who had knowledge about ASD and discussed next steps with them felt much more supported than those who did not.

With respect to friends and family, participants did not find it necessary for them to have knowledge about ASD. However, as stated by several participants, they felt a “special bond” with other parents or friends who may have a child with ASD. Therefore, though any support from friends and family was appreciated, the support that participant’s may have received from others who have children with ASD was highlighted. It is important to note that participants did not necessarily value support from those who have children with ASD higher than those who did not; rather, they simply viewed it as an added bonus.
Ability to listen

Teresa:

…My doctor was very good…by providing information and just asking how I was. I found out that he (child) had Autism months after moving to this country and months after leaving my husband. We came here, we split up, and then I find out that my kid has Autism. My doctor was very much “How are YOU doing” and asked whether I needed support groups because he knew I was new to the country. He was great.

…Someone to talk to would have been beneficial. The most useful things I took were through parenting groups. It really, really helped me to sit there and talk to other parents at the end of these things. They all agreed that listening to each other’s stories and what we were doing and what was helping us and giving each other permission to say “I have kind of screwed up this week” was helpful. Being honest with each other is super helpful, but it is not readily available because we all said that we will be able to continue this group beyond this but it is such a difficult thing to do. It was hard enough to get to that course…

Amelia:

… We were lucky that we had our speech pathologist. To this day, I email him and he is fantastic, he went beyond what his job called for. He sat me down a number of times without A and told me what to look at and he was extremely supportive…

Sara:

…I have a few friends that do work as regular teachers and work in Special Education and there can be a benefit for sure but I am thinking about my family and friends and I do not know whether it really matters besides their willingness to listen and support me and hear me out.

Maria:

I think I have good friends right now who understand the situation but the thing is that we cannot be as consistent as what we had in my home country….We can’t meet at a movie house or a mall or a park. It is just hard. The support is really on the phone, which is not always enough for me…

A professional’s ability to listen in addition to their knowledge about ASD is what brought them to the next level in supporting their client. Their clients in this case being the participants. Listening to what the participants were saying made them feel heard and also
acknowledged that supporting a child with ASD is not easy. Often, so much focus is placed on the child and the tasks needed to ensure their care that professionals forget that it is the primary caregiver that is the facilitator. Therefore, the simple act of listening and inquiring about what the participant needed made the difference. Some participants stated that they had certain professional’s in their supply of contacts that they used for advice when they needed and felt very positively about this form of support.

Participants who felt emotionally supported also had family and friends that they said were willing to listen and support them. The support came in a variety of ways but the constant theme to those who felt supported emotionally was that they had someone to go to that they could speak freely to without judgement. They could vent their frustrations in a safe space to someone that understands that they are doing their utmost in a difficult situation.

**Macro Themes**

Systemic issues were a point of discussion for all participants. Even if the question was not directly about “the system”, the response would often lead to this theme. In the current study, “the system” refers to the complex web of organizations, centres, professionals, and services that a primary caregiver of a child with ASD is required to navigate. Participants felt that the information they need as primary caregivers exists and that the services and supports accessed were of good quality. However, the consensus amongst all the participants was that the system needed to be changed as its current organization hindered their ability to access these services.
Many of the comments and responses could easily fall under the theme of “accessibility.” However, in order to highlight the concerns and points of contention for the participants, the themes were separated in order to be individual points of analysis. Therefore, for the purposes of this study, “accessibility” addressed physical, cultural, and language accessibility. “Care coordination/Service navigation” dealt with obtaining information, referral process, and management of multiple services and programs. “Waitlists” looked at any mention of prolonged wait to access supports or services for either the child or the participant who is the primary caregiver. “Program structure” spoke to the necessity of greater variety of program availability. Lastly, the “need for work flexibility” involved commentary on how traditional work structures are not conducive to a primary caregiver supporting their child with ASD.

**Accessibility**

Amelia:

…You might get an immigrant parent who doesn’t understand the language. There needs to be cultural resources as well.

Sara:

…Maybe if we had the same things that are out there for parent supports but over the internet, so you can still participate but be at home…just a general parent discussion group that could be topic based or not. Maybe every Thursday at 7:30pm or whenever it might be and people can just log on and participate that way. I think it would be cool so that people who don’t have cars or even during winter when it is also hard. I work full-time so I work and rush to travel and pick my kids up and drop them off and then head to Bloorview for the parent talk…

Language, cultural and physical accessibility were points of concern for some participants. Toronto is a natural settling point for newcomers. Newcomers do not necessarily have a good command of English or French, which are the languages resources are often printed in. It was also discussed how outside of language inaccessibility, the concept of disability is
stigmatized in some cultures. Therefore, better cultural resources are also needed to make the concept of disability for accessible for those who are not as familiar with the concept. Without increasing language and cultural resources, a certain faction of children will not be diagnosed. Not being diagnosed means that the child would not have access to certain supports that they may need, which could affect their lives significantly.

Physical accessibility is a concern that can affect everyone. Participants often stated that they had to travel from various appointments using public transportation. Though participants acknowledged that support could be accessed from a number of places across the city, it does not necessarily mean that centres that provide services and support are conveniently situated. The example given was Holland Bloorview Rehabilitation Hospital, which is well known for their ASD services and programs. Even from the closest bus stop, it is still necessary to walk a fair distance (500m) to the hospital itself. If you have a child with a disability, the walk could seem even farther. When establishing locations for services and programs, it is necessary that these locations are as accessible as possible for caregivers, whether or not they have a vehicle.

**Care coordination/Service Navigation**

Teresa:

Yes, an umbrella organization would have been more informative to help me understand everything that was going on. There were several organizations that handle different things and some of them overlap. It is very overwhelming…

Aside from the fact it was very disorganized and confusing I felt like there was probably more available than I was given access to because it was confusing…

Amelia:

It would just be nice to get a list of services that is not just a bunch of people that you can call and feel very calm for an hour, but very practical speaking people. Sure, give me some therapists to help me deal with the diagnosis, but there also needs to be a more organized service list…
Maria:

It was really bad. I just remember coming over and trying to navigate the whole process of getting a doctor in order to refer my child to a developmental pediatrician. It was hellish. The only people I could get help from were other parents and sometimes it was just by chance. My child had some cleaning at a dentist and the dental assistant asked whether there was something wrong with my child…I said yes…and she asked whether she had a diagnosis already and I said I still needed a Canadian diagnosis. I was getting information from strangers who have had the same experience as I. That is how I got a diagnosis.

It was not really the organizations or the hospitals or the system that really helped me out. It was the mothers who have kids with disabilities that helped me. Even now.

Sara:

Maybe more coordination of referrals…it would be ideal if everything was centrally coordinated. I did a lot of running around and when I think of things after the fact, you have to continue to go back to your family doctor and get separate referrals. Each referral had a different process and it would be nice if there was a catch-all.

Ideally, during a routine check-up a family physician notices some of the warning signs of ASD and makes the appropriate referrals in order for the child to be properly assessed. However, based on the responses from the participants, it was not that straightforward for everyone. When hearing the participants recount their process of getting their child diagnosed, it seemed like a process of trial and error until they stumbled onto a centre or hospital that could do the assessment. The assessment was only the beginning of trying to make sense and navigate a system of services that participants needed to access for their child.

The most common word when discussing service navigation and care coordination was “overwhelming”. More than one participant stated that either they or their partner was required to take time off work to “understand the system”. In particular, Ava stated that her partner had to take one month off work to map out how the system worked. The feelings of being overwhelmed stem from the fact that there does not seem to be a standard issue service navigation map given
as a resource upon diagnosis. Participants were required to piece together the system independently and learn the significance of each piece by themselves. This process would be easier if there was only one agency offering the services. However, each service or program is currently offered by multiple agencies. In addition, different agencies do not have the same eligibility criteria.

Participants stated the obstacles from accessing programs most often revolved around the age of their child, the degree of functioning, and their home address. One participant shared that their child was not able to access IBI programming because there was a two-year waitlist; by the time their child was able to get through the wait list, they were considered too old for the program. Furthermore, some programs are geared towards higher or lower functioning children and participants are forced to figure out where their child fits best within the overall programming options. Additionally, each agency has jurisdiction over a specific area of the city. If an individual’s home address falls out of the agency’s area of jurisdiction, it can disqualify primary caregivers from accessing services there. A last complication stated by the participants is that accessing services from one agency can disqualify you from accessing services from another.

This means that when a primary caregiver is attempting to access services, the expectation is that they have a base level of knowledge of the eligibility criteria for each program, as well as the agency that is offering the program of interest. It does not seem supportive to primary caregivers or an efficient use of their time to require them to keep track of where and when and whether their child is eligible for service. Keeping track of eligibility criteria and registration is on top of the number of referrals that they may need to obtain to access the service
**Waitlists**

Maria:

The one thing that is really annoying is the waiting list.

…I don’t know…why do I have to wait for my daughter to get that service and it is only eight weeks. How does that help her? Sometimes I am really angry. I really, really need to find another therapy so that there is a consistent therapy for her. Why are they giving her ABA services that are eight or twelve weeks long and then it stops, when they know scientifically that they need to be providing consistent programs in order for her to improve…

…I really needs to be improved. One year waiting list…it is just too much waiting. The program itself is great, the objectives, the workers are great. It is just the waiting.

…I think when I can see that there is a consistent, continuous program for them. Not being on a waiting list and not getting service at this hospital, then you have to go somewhere else and somewhere else again. I just want to go to one place. I just want it to be easier to access the services…

Sara:

I think a lot of kids need to access services like Occupational Therapy (OT) and Speech and Language (SLP) and a lot of them are private, and if they are not, there are really long waiting lists, and if you don’t have insurance or even if you do it is very expensive.” We had him in OT last summer which my insurance benefits actually don’t cover, which I could afford but a lot of families might not be able to. Having more affordable services or shorter waitlist so that more families can get through to those services would be a benefit.

…I think waitlists are an accessibility issue. They are way too long. He has been on waitlists for ABA services since he was 2 and half years old and he is 4…

Amelia:

…I have been on waiting lists and I have given up on that because it is frustrating to deal with…

Bringing up the topic of developmental services often leads into a discussion of the waitlists that individuals have to be on before that they can access services or programs. The very first waitlist is to get an ASD diagnosis assessment. From then on there seems to be a
waitlist for every subsequent service or program that the child may need. Based on what was said by the participants, this is problematic for a number of reasons. The first reason is that children with ASD typically need to access more than one service. After diagnosis, it does not seem to be unusual for children to need to access occupational therapy, physical therapy, and/or speech and language services on top of the recommended behavioural/social skills groups specifically for children with ASD. Participants stated waiting anywhere from six months to two and half years for a service or program. Some are still waiting.

For primary caregivers, waiting is the hardest thing to do, as nothing is being done during this period. Having to wait over six months for diagnosis is terrible when the first thing that every primary caregiver is told is that early intervention is best practice (Wilkinson, 2010). One participant referred to having to wait as “heartbreaking”. Another participant simply asked, “What are we supposed to do while we are waiting?” This is an important question to address because it is a point of frustration. It should also be noted that best practice for ASD therapy is continuity (Wilkinson, 2010). Despite this, ABA services, the most popular form of publicly funded ASD therapy, is delivered in blocks spanning eight to twelve weeks, and there is a waiting list for each block.

Waitlists have the potential to look very different depending on the type of treatment that the child is accessing, therefore affecting families differently. For instance, as the Auditor General highlighted in 2013 the structure of IBI versus ABA is very different. For IBI, once the child is admitted into therapy they will remain in therapy for two or three years; readmission is not an option once discharged from IBI therapy. However, ABA therapy occurs in blocks of two to six months, and the child can reapply after they have been discharged from their block of treatment; but that means going back on a waitlist. This particular difference in program
structure affects whether a child will be on a waitlist once or multiple times in order to access the same amount of therapy.

It should be mentioned that the topic of wait lists has been reserved for publicly funded services and programs. If an individual is willing to pay for the service or program there is no waitlist. This is a course that many are forced to take if they feel like the wait is too much for their child. Ava said they paid for the ASD diagnosis assessment independently because the wait was too long. All but one participant reported paying for a service or program independently, which ranged from private therapy to ASD specific programs. The participants reported costs for private services ranging from $20/hour to $150/hour. These costs quickly accumulate and are not affordable, and therefore inaccessible, for a large portion of the population.

**Program Structure**

Sara:

They don’t often match when parents work and I work full-time 9-5, and groups start at 3. If I were to bring him to that group I would have to leave my work to get to his school at 1:30 to get him back on time and bring him back at 3. No job is going to say yes to taking off half the day every Friday…

Having groups that are offered at different times or weekends would be better.

Actually right now I have paid somebody to pick him up every Friday and bring him to his group…

…it is so hard for some families to bring their kid to TPAS or the sacrifices they make to bring their child because the times overlap with their job. We don’t start earlier, so it is not possible to drop your kids off early and get to work and TPAS ends earlier than when most people end their job. It is tricky.

I just feel like the time slots that are offered make it really hard.

Amelia:

They talk about respite services and I get very frustrated because there are not a lot of times that are suitable because I work and have to maintain a full time job.
It boggles my mind that there are minimal services in the evening and weekends. There is nothing respite wise that can be done during that time. As a working parent I don’t need relief during the day…

I find publicly funded programs that not every kid is the same and you get a bunch of kids that may not be compatible…

The greatest issue with program structure was not how the program was being delivered but when. Participants reported that ASD programming typically runs during the day, while they are at work. Meaning that in order for their child to participate in ASD programs such as ABA or IBI, the caregiver, if they are working, has to have flexible work hours or be able to take time off work to accommodate the inconvenient timing of these programs. Though there were some participants who were stated to be lucky enough to have flexibility within their work schedule, they recognized how it is not feasible for many other primary caregivers. For some primary caregivers they have to choose between working and their child’s therapy. The financial pressure, which they might incur from losing work hours, forces caregivers to make ASD treatment secondary. This is unfair to both the caregiver and the child.

Participants stated that it would be beneficial to have programs available during the evenings or weekends not only for their child but for themselves as well. Services such as respite or counseling are not easily accessed if a primary caregiver is working since most of the availability occurs during the day while they are at work. As one participant says, “As a working parent I don’t need relief during the day”. Outside of the structural issues of program scheduling, participants commented on how for both primary caregiver supports and their child’s programming the group composition is not always ideal. Since ASD is on a spectrum, it is important for a child who is participating in a program to have a compatible functioning level with the others. Participants reported that this is not always the case in publicly funded programs perhaps more care should be taken to ensure this. The same rule applies to primary caregivers. If
an agency is delivering a primary caregiver workshop, they should be cognizant of the level of functioning of the primary caregivers’ children. Otherwise, the facilitator will be teaching strategies or skills that may only apply to a portion of the group, not making effective use of the rest of the group’s time.

**Need for Work Flexibility**

Sara:

…systemically having employment standards around flexibility or extra unpaid days that you have the right to access that you can use for your child with a disability to pick them up or take them to an appointment…

I had one family years ago actually pull their kid out of TPAS because they were at risk of losing their job because they had used so much sick time and vacation. Their workplace was either you have to figure something else out or we have to let you go. How do you make a choice between your job and your kid accessing TPAS? We tried so many different things but we couldn’t get it to work…

Amelia:

…I work for a company that is very good about the time I have to take off. They give you fifty hours of personal time and four weeks of vacation that a lot of other places won’t do…

Services operate during the day and it eats into a family’s time at work. In many ways I am lucky because I have some flexibility at work. I have talked to some families I have worked with and they don’t.

The topic of work flexibility is a direct outcome of the way that programs are scheduled. If programs were scheduled outside of the working hours, the need for work flexibility would not be as high. For those participants who have flexibility within their work schedule, they recognized that they are lucky and it has been a benefit to them. These participants did not have to choose between working and their child accessing the services they need. One participant suggested that if you have a child with a disability, there should be certain policies that come into
action allowing the primary caregiver to have certain flexibility at work, with respect to the hours that they come in. Alternatively, a transportation service that provides a shuttle service to and from programs should be provided to relieve the stress that caregivers may have from scheduling time to shuttle their child to and from therapy. Barring that, primary caregivers with dependents who have special needs would be able to access extra-unpaid days. Though allowing a caregiver access unpaid leave would alleviate the stress of putting their job at risk, it would be adding to their burden by simply not paying them for that day. Having policies such as those in place would mean that it is being recognized that primary caregivers who have children with disabilities do have more responsibilities to take on in order to ensure their child’s wellbeing.
Chapter Five: Discussion

This chapter discusses the thematic findings as they relate to existing literature. More specifically, in depth discussion around the issues of care coordination will be provided as it was the one theme mentioned by all the participants. In addition, this chapter will examine how the community of practice model may be applied to these findings. The potential avenues of applicability are not only exciting, but also feasible. Lastly, the implications of the findings from this study and areas of future research will be explored.

Micro Themes of Support

The findings showed an interesting interaction effect between “knowledge about ASD” and the “ability to listen” when examining who was providing the support. If participants were discussing a professional who they found supportive, they emphasized that they were knowledgeable about ASD. When participants were discussing the support they receive from friends and family, the emphasis was on their ability to listen. However, for both professionals and friends and family, the ideal was if the individual possessed both knowledge about ASD and an ability to listen.

The basis for emphasis being paid on one element of support over another seems to be due to the fact that primary caregivers have expectations based on whom they are interacting with, and do not feel supported when these expectations are not met. For instance, if a primary caregiver is interacting with a professional, the expectation is that they know the relevant literature and are able to guide accordingly. When interacting with a friend or family member, the caregiver often seeks emotional support in the form of judgement-free listening. These findings partially align with past literature. It was confirmed that Zablotsky’s (2013) finding that general supports (friends and family) providing emotional and relational support to primary
caregivers should not be discounted. However, he found that these supports are less effective for reducing parental stress than support from others who have children with ASD. This second finding was not supported by this research. Primary caregivers who have parental supports did mention that they have found such support beneficial, but they did not seem to value it higher than the general supports that they also receive.

Past literature, such as Whitaker’s (2002) study on supporting families within a professional setting, demonstrated that parents found the knowledge about ASD most useful, which corroborates the findings in this study. Similarly, having a friend or family member who has the ability to listen was also cited as important for a primary caregiver to feel supported (Guralnick & Hammond, 2008). The studies discussed these supportive elements under the headings of parenting and general support. However, in conjunction with this present study, the findings show that there may be benefits in investigating the themes of support independently. By investigating an individual’s “knowledge about ASD” and “ability to listen,” present findings suggest more detail is needed about what information is expected from professionals and how to foster better listening skills.

**Macro themes of system failures**

The prevalence of macro themes was an unanticipated finding of this study. During analysis, each theme was discussed separately, but it does not feel right to explore them individually because the interplay between each theme is what forms the greater system. Based on the experiences shared by primary caregivers it is more useful to discuss each theme as a part of the whole. With these interactions in mind, discussion around systemic issues was popular amongst participants.
Analysis of the interviews highlighted language, culture, and physical accessibility concerns; a confusing and overwhelming service system; long waitlist times for services; impractical time slots for programs and services for working primary caregivers; poor program fits for children; and concerns around work flexibility. Despite the trials and tribulations that come with accessing the public system, those participants who remained in the public sector stated that when they eventually access the services that are, for the most part, good. “Good” being defined as a standard that they believe is suitable for their child. However, according to accounts given by the participants, it is the waiting before and in-between services that heighten their stress.

It was hard to determine how each participant learned about the diagnostic referral process. To get their child assessed for ASD, participants ranged from going through their general physician to finding out information from strangers. The waitlist for diagnosis seemed to be an average of six month, with the exception of one participant who paid privately for an immediate assessment when they heard how long the wait would be. After the diagnosis, caregivers were responsible for obtaining services for their child. This meant not only more waitlists, but also navigating the service system and keeping track of multiple referrals. Some participants reported being on the waitlist for up to two years, and some are still waiting. Even though most are satisfied with the service once they get through the waitlist, one participant stated that within publicly funded services, they do not always match the functioning levels of the children when creating groups for each program. In addition, working participants highlighted that services and programs are offered at times that conflict with full-time work schedules.
Based on accounts from participants, the above is an average experience for a primary caregiver with a child with ASD trying to access services. These accounts match the findings in the literature that state that caregivers find it challenging to deal with a poorly coordinated and unresponsive service system (Green, 2007). Though all systemic issues that were discussed by participants are important and relevant to the whole picture, all participants repeatedly mentioned the lack of coordination between services, centres, and referrals. “Confusing” and “overwhelming” were terms most often used to describe the system. What they were touching on was the lack of care coordination to navigate services. The idea is that with proper care coordination comes easier service navigation.

Cursory research like that done by Green (2007) shows that the research community is aware of the challenges that come with systematic problems. However, extensive research has not been done on the topic of how to improve the service system for primary caregivers of children with ASD. Arguably, any improvements done on the service system with the ASD population in mind would benefit other individuals who require complex care. The suggestion from participants that better care coordination is needed should be examined, but first it must be explained.

The term “care coordination” is widely used, but it is most commonly used within health and social service fields. Broadly speaking, care coordination refers to a range of roles that offer seamless support to individuals who have complex health, community, and social support needs (Heslop, Power & Cranwell, 2014). The role of a care coordinator is identified as the most important for individuals who need to access multiple services. Participants believe that a lot of their stress would be mitigated if there was only one service access point, or referral coordination, or coordination between agencies.
Haney (2011) reported that primary caregivers said that poor collaboration between agencies working with their child with ASD and a lack of continuity between supports has a compounding effect on parental stress. Haney’s findings corroborate what participants shared in this study. Participants from this study discussed the lack of continuity between supports when the topic of waitlists is brought up. Participants also wanted to know what they should be doing while waiting. Professionals gave primary caregivers little support in this regard with one participant reporting being told to “just wait.” There has not been any research on ASD-specific waitlists, which is unfortunate because waitlists are a reality for both the child and the primary caregivers. Further research should inform how to improve supports for the child and the primary caregiver while they wait for services. “Just waiting” or paying privately should not be the only options.

Other systemic commentary revolved around program structure and accessibility. Program structure was discussed in two ways: program fit for the child and scheduling. Currently, publicly funded ASD therapy programming outlined by the Ministry of Children and Youth Services (MCYS) is limited Intensive Behavioural Intervention (IBI) and Applied Behavioural Analysis (ABA). Since ABA and IBI are the only publicly funded ASD therapy programs, more care is needed in ensuring that the group of children in each block of programming are properly matched. Matching is important in behavioural therapy (Zucker, Perras, Perner, & Smith, 2009), because ASD operates on a spectrum and if the discrepancy of functioning is too large between children in a group, it affects the effectiveness of the therapy (Zucker et al., 2009). One participant said that her child was particularly sensitive to such dynamics and it was very frustrating when her child picked up behaviours from lower functioning peers in his ABA group.
Working participants stated that the time slots for ASD programming, services and supports are not conducive to those working full-time. Participants found that there are not enough evening and weekend time slots, forcing them to make alternative work arrangements or pay for someone to take their child to appointments. The participants in this study who worked had flexibility in their work schedule. Nevertheless, they recognized that for primary caregivers who do not have such flexibility their jobs might be at risk. Despite having work flexibility, working participants still had to pay someone to shuttle their child at times, and while it was affordable for them, they remarked that others might incur a significant financial burden.

The findings around the need for work flexibility parallels what is discussed within the literature. As highlighted in work-family research, coordinating work and family needs is a stressor for any family. However, for a family that has a child with special needs that requires multiple appointments, it is a point of great stress (Matthews et al, 2011). It is not unusual for working primary caregivers to be forced to modify their work arrangements or cease working altogether in order to meet the needs of the child (Leiter, et al, 2004). This is particularly relevant as one participant who provides ABA services recounted a story about how she had a client that had to choose between therapy for their child and employment. In order to avoid caregivers being required to make such a decision, it is necessary for employers to be aware of the complicating factors of having a child with special needs and allow for flexible work schedules or working from home.

Though all participants are women, based on the information from this study I do not necessarily feel that gender plays a role in caregiver marginalization. I believe that the caregiver, whether it is a man or woman is forced to make compromises if working full-time while trying to access ASD treatment for their child. What I believe does make more of a difference is the type
of job a caregiver has. Those who work white-collar jobs are more likely to have work flexibility. For those caregivers who work service and manual labour jobs, it is harder to obtain such flexibility. This may simply be because the tasks that are associated with white-collar jobs are easier to be taken home than service and manual labour jobs. However, as we know, the type of job that an individual has is often intimately connected to education level, class, and race. Which means if we follow the logic that those occupying white-collar jobs are more likely to obtain work flexibility than others, it means that the children of those who cannot obtain such jobs are less likely to be able to obtain treatment.

The accessibility needs for the ASD population are large and could be defined in a number of ways. However, this study focused on physical, language, and cultural accessibility. Physical accessibility is an issue for those participants who rely on public transit. For example, one participant said that it could take up to an hour and a half to bring her child to their program. Furthermore, ASD centres were located in places that were difficult to access via public transit. Some centres required walking 500 meters from the closest transit stop, which was stated to be too far for some participants if their child was acting out that day. Having a child with special needs can make walking a few blocks more complicated. Geographical considerations should be made when planning where programming and service centres are to be established to ensure that those who need to use public transit find it as convenient as those who may have a vehicle.

One participant noted that despite living in a city that is considered multicultural, the resources for ASD are linguistically and culturally limited. This finding is problematic not only in terms of spreading ASD awareness to diverse communities, but also for delivering services. In a study on barriers to accessing services for young children, Williams, Perrigo, Banda, Matic, & Goldfarb (2013) found that families that did not speak English found language to be an even
greater barrier to accessing services than lengthy waitlists, inadequate finances, or transportation. Given that all participants in this study were English-speaking, it would be informative to examine the experiences of primary caregivers who are not native English speakers.

**The Communities of Practice Model**

Staying true to the social constructionist paradigm values, the individuality in relation to and in interaction with broader social structural factors were appreciated and taken into account. During the thematic analysis of the transcripts great care was taken to ensure that that the individual experiences were not generalized to suit my needs as a researcher. The consequence was a robust thematic analysis that touches on the caregiver stressors that come with being a primary caregiver of a child with ASD and the supports that they may or may not find helpful in reducing this stress.

The majority of the stressors identified by participants involve the service system. At present, there is no support in place to meet the needs of primary caregivers. Constructing this support would be difficult, but it is important, not only for the primary caregivers but for their families as well. Based on the findings of this study, an ideal support would be able to improve care coordination/service navigation, program structure, and accessibility issues, while connecting caregivers to each other.

The strength of a community of practice model lies in the definition. The formal definition of “community of practice” (CoP) is a collection of people bound together by location, purpose, activity, values, desires, and perhaps labels (Lave and Wenger, 1991). The research on CoPs, though popular in a number of fields, is only starting to grow within disability research as the benefits become more apparent (Lawthom, 2012). Wenger (1998) outlines three aspects to a community of practice: mutual engagement, joint enterprise, and shared repertoire. *Mutual
Engagement is defined as individuals interacting co-operatively; joint enterprise is described as having a shared endeavor; and a shared repertoire is a set of common resources of language, styles, and routines, which allows for an expression of their identities as members of a group (Wenger, 1998).

The nature of the model makes it flexible and lends legitimacy to groups like primary caregivers who live in a world that values professional experience over lived experience. My suggestion is to use the community of practice model unconventionally in conjunction with the findings from this study in order to provide support to primary caregivers. Through past literature, and this present study, it is clear that primary caregivers benefit from individual support. The most important characteristics of individual support are knowledge about ASD (if support is being accessed formally) and the ability to listen (if the support is coming from an informal source, such as family and friends). I believe fostering a community of practice amongst primary caregivers could be a means of support that ideally balances both the knowledge about ASD and being among individuals who are able and willing to listen. In addition, the uniqueness of each individual is not lost, but rather is balanced against the commonalities that they may share with others.

Informally, primary caregivers who have friends with children on the spectrum already unintentionally fulfill these core components. One could argue that this oversight is why the participants who have this medium of support reaped so many benefits from it. When talking to participants, they all agreed that they would appreciate a parent group to participate in, but each had slightly different ideas of what it would look like based on their individual needs. In implementing such a parent group the systemic issues that were highlighted by the participants would also be addressed.
One participant suggested the idea of an online parent group as a possible solution to accessibility issues. However, though not mentioned by any of the participants, many parent groups do presently exist online, which brings about the question whether caregivers are being connected to the appropriate resources. It would be useful to explore whether appropriate online parent groups exist for the region of Toronto. If not, it would be beneficial to conduct one for primary caregivers to access support from home at a time that is convenient for those who work. Issues such as waitlists and care coordination cannot be address as it goes beyond the scope of a parent group, but within the group issues with service navigation have the possibility to be clarified by group members.

It should be noted before continuing that though an online CoP would resolve certain accessibility issues, but requiring a computer to access the group would be an accessibility issue in itself. Those with technological limitations would be disadvantaged. Despite this, the benefits of online support could outweigh the disadvantages. The benefits come from the potential to effectively support primary caregivers by not only allowing them to access informative resources that are relevant to their child but, if needed, emotional support as well. The vision would be to host a primary caregiver site if it does not yet exist for the region of Toronto that possesses two core components: an online support group and reliable information relevant to ASD (strategies, current research, and professional advice). An online modality will allow for flexibility, but more importantly, such a format allows for primary caregivers to pick and choose what they wish to participate in based on self-identified needs. This feature respects and recognizes the variability of experience of those caring for a child with ASD.

Modelling an online support group after a CoP would require three main structural elements to exist: a domain of knowledge, which defines a set of issues; a community of people
who prioritize this domain; and the shared practice the community is developing to use within their domain (Wenger, 2002). Therefore, primary caregivers of children with ASD (community) would be determining what resources and strategies are effective (practice) with respect to caring for their children who may have a wide range of needs (domain). It is not a far stretch for an online support group to mirror such a structure. In fact, a CoP is likely to be developed organically as primary caregivers are motivated and looking for support. The role of the professional would simply be to create a space that is safe and conducive to the development of a CoP ensuring that each participant feels heard and supported.

**The Issue with Care Coordination**

Developing a community of practice amongst primary caregivers can assist with alleviating a number of issues but it cannot address the lack of care coordination. And, since participants indicate that they believe care coordination is the “solution” to the fragmented system problem, a more in depth discussion on the topic is necessary. The logic suggests that a care coordinator would be the bridge that brings the fragmented system together, however, literature on care coordination discusses the challenges of turning this theory into practice.

Care coordination is used to refer to a range of roles that offer seamless support to individuals who have complex health, community, and social support needs (Heslop, Power & Cranwell, 2014). Effective care coordination involves the adoption of standardized criteria to help identify those individuals in need. In addition, each organization or community would have a designated care coordinator who provides a single point of entry (American Academy for Pediatrics, 2012).

Care coordination operates best as a concept because there are many barriers to effective care coordination in practice. The most notable barriers are: a lack of communication among
health care professionals and organizations involved in the care of an individual; insufficient acknowledgement for the amount of time and work needed to provide quality care coordination services; and a lack of an organized system of care coordination with multiple service delivery systems involving multiple care coordinators (American Academy for Pediatrics, 2012).

To further complicate the matter, there is no standardized method to care coordination, and tactics often vary from organization to organization (Lemieux-Charles, Chambers, Cockerill, Jaglal, Brazil, Cohen, LeClair, Dalziel & Schulman, 2005). For instance, as stated by Lemieux-Charles et al. (2005), though care coordination often involves a case manager, it is not necessarily needed. It has been shown through studies (Meyer, Jekowsky, & Crane, 2007) that the necessity of case managers comes from individuals feeling lost in “the system”. This feeling was brought up by participants and was the source of ample frustration.

“The system” that individuals are referring to is a system of services and care that is fragmented based on individual organizational mandates, roles, and functions (Yip, Myrtle, Wilber, & Grazman, 2002). Therefore, discussing bettering care coordination is closely aligned with service integration (King & Meyer, 2005). Naturally, services integration is relevant to the same individuals that would benefit from case coordination (Yip et al, 2002). Integration is often thought to result in positive outcomes for the targeted populations as the intention of integration is to close gaps in service coverage, timeliness, ease of navigation, and an increased efficiency of delivery services (Fisher & Elnitsky, 2012).

In fact, care coordination, though often referenced by participants as something they feel would help reduce their stress, may only be a short-term “solution” to the systemic issues they highlighted within this study. As the literature illustrates service integration may be a more worthwhile investment in time and funding with outcomes that have more longevity. A key
example of integration would be the *Ontario Special Needs Strategy* that is presently being implemented. A key element of this strategy is to “make supports and service delivery seamless”. The proposal by MCYS (2014) to ensure that the goal of seamless service is reached is to integrate the delivery of rehabilitation services (SLP, OT, PT). Though the strategy is still in the early stages of implementation the move for the Province to integrate services for children with Special Needs is recognition a long-term solution is a better investment of time and resources.

Much like the term “care coordination” the term “service integration” is used widely and with variability. Fisher & Elnitsky (2012) found that within the literature, integration can occur at a variety of levels and will look different depending on the level it occurs on. Examples of levels would be the case/client level versus the administrative /management level, which could be viewed as “service versus “systems” level integration. Agranoff (1991) noted that integration involves three interdependent public management activities. These include (a) policy and strategy development at the program implementation level, (b) operating plan with a component that considers external support, and (c) local systems development at the client level.

Typically, as Hassett and Austin (1997) highlights, service integration has been approached from two different standpoints, one being that there is a need to fill a gap in services by implementing new services and a second that attempts to provide existing services more effectively. This notion corroborates the Fisher & Elnitsky (2012) argument that the main rationales behind integration are efficiency and efficacy. Presently, the literature does not illustrate a model of best practice when it comes to service integration. However, the most common model being adopted according to the literature is “Networks”.

Networks can range in size and scope, depending on the intention. Nevertheless, the core element of reducing the consequences of a fragmented system stays consistent across networks
(Provan & Milward, 2001). Despite networks being the most likely means to reduce the fragmentation of care (Lemieux et al, 2005), they do not come without barriers. Bringing different agencies and organizations together from different fields also means bringing together different mandates, funding allocations, eligibility criteria, and jurisdictions. Rather than focus on the barriers that may occur in networks of care, it is more productive to focus on what an effective network looks like.

Provan & Milward (2001) state that an effective network aims to enhance the capacity of organizations to solve issues and to service clientele by improving access, utilization, responsiveness, and integration, while maintaining or reducing costs. In addition, Yip et al. (2002) continue to state that improving inter-organizational communication between diverse entities and centralizing activities through the co-location of services should also be central aims. In order for this to occur, the interests of the target population along with the members of the networks must be satisfied while building a cooperative network of inter-organizational relationships that move towards a common goal: to collectively provide services in a more effective manner than a system based on funding and services (Provan & Milward 2001).

Regardless of what form service integration takes, it appears that aligning services and systems would have more long term benefits than care coordination, and in fact, possibly remove the need for care coordination altogether. Piecing the fragmented system back together, though a more arduous and politically charged task, should take precedence if primary caregivers and their children are indeed the priority.

**Limitations**

This was an exploratory study and, as such, the participant representation was very small. However, I hesitate to call this a limitation, as I feel that exploratory studies offer a flexibility in
outcome that descriptive or explanatory studies cannot offer. For example, the interview style chosen was semi-structured, as per other exploratory work (Crouch & McKenzie, 2006). Semi-structured interviews were advantageous because a degree of flexibility is afforded with respect to how participants can respond to the questions, while at the same time ensuring that the questions of interest are being answered. However, with such flexibility comes the risk of answers being indirect and convoluted. It takes some time before the participant reaches their conclusion, meaning that in later analysis, a portion of the response may not turn out to be directly pertinent.

The rest of the limitations largely lie within how I chose to represent the population. The first being that “primary caregiver” has been defined as the mother of the child in this study. However, it should be recognized that other individuals such as fathers, grandparents, and other legal guardians may also be fulfilling the role of a primary caregiver and their needs may be different from the mothers’. The supports and experience of supports could be affected by the gender of the caregiver. However, due to the parameters of this study, gender similarities/differences could not be established as a finding. Secondly, a general diagnosis of ASD was the only requirement, but it is necessary to note that severity of ASD differs and with that difference comes a need for varying levels of support and resources. It should also be acknowledged that by targeting primary caregivers who were associated with autism specific organizations, I already knew that they had accessed to some support for their child in the form of behavioural therapy. By default, this means that my participant pool did not include primary caregivers who had no access to support. This increased the likelihood that my participants were better versed with the system and had a stronger support system than those who have yet to access services. Thirdly, the process of participant invitation took place through email. Meaning
that I was only able to reach participants who had access to technology, and/or technologically fluent. Lastly, since I am only fluent in English, I was not able to incorporate primary caregivers who do not speak English. This meant that I was not able to capture the difficulty that comes with accessing resources and supports as a primary caregiver who speaks a foreign language.

The final acknowledged limitation lies within geographical context. Though the findings of this study mirror much of the research done on the topic of caregivers and ASD, they should only be comfortably generalized to the area of Toronto and other regions that would be classified as urban in Ontario. The systemic issues of rural regions could be very different than those found in this study.
Chapter 6: Conclusion

Implications for Practice

The findings from this study have implications in the following areas: addressing how to support caregivers whose children are on waitlists for services, assessing how to assist with care coordination and service navigation, expanding the schedule for programming times, connecting caregivers, and advocacy.

There is no denying that caregivers are frustrated with waitlists. The findings have shown that caregivers have to wait anywhere from six months to two and a half years for services for their child. If simply waiting is not frustrating enough, caregivers are not given any alternatives about how to assist their child in the interim. Professional services should be looking at how to assist individuals with ASD and their families while they are waiting for the supports they need. Just waiting should not be the only option available.

Findings also show that there is room for improvement around care coordination and service navigation. Caregivers should not be feeling overwhelmed when accessing services for their child. As a whole, the service system needs to assess how to better align their programs and services. Better alignment will allow caregivers to move through the system without feeling as overwhelmed. At the very least, a service navigation map should be developed for each community to be given to caregivers upon receiving their child’s diagnosis.

As the findings indicated, the program and service times as they currently stand are not conducive for working caregivers. Therefore, an implication of my research would be raising awareness for the need of expanded program and service times to evenings and weekends, and the benefits that would come with it. This adjustment would have the ability to alleviate a great
deal of stress from caregivers who work full time. It would also remove the risk of caregivers being required to choose between services and support for their child and earning a living.

Furthermore, this study demonstrated that there are benefits to connecting caregivers to each other. Through such an exchange, caregivers could receive advice and support from people who have gone or are going through a similar situation. Developing creative and accessible ways to connect caregivers should be a priority to service providers in this field. Bringing caregivers together ties into the idea of increasing advocacy. Connecting families together strengthens their voice, which can assist with advocating for changes that they feel they need. Advocacy will help increase the understanding of what ASD is and the challenges that come with it.

**Future Research**

The implications of this study have the potential to have a large impact on the ASD field. There are a number of areas of future research that have the potential to improve the caregiver experience. These areas include policy, system change, and research that are specific to the geographical region of Toronto.

The exploratory nature of this study allows the findings to be the starting point for future studies around supports for primary caregivers with children who have ASD. For instance, considering that the issues around waitlists is tenuous for both service providers and those trying to access those services, it is a wonder that research around waitlists has not been previously tackled. There are many potential areas for research around waitlists, especially around supporting primary caregivers. As the present system stands, waitlists are inevitable. Therefore, it would be useful to know what primary caregivers are doing instead. Are they paying for services privately? Are they attempting to take on the role themselves? Are they waiting? We do
not know what is being done in the interim, and it is crucial to find out how primary caregivers are supporting their children during this time, in order to better support them.

Systemically, it would be useful to compile and compare the different eligibility criteria for each of the ASD services and programs offered within the Toronto region. Reviewing services and programs as a collective would provide better data on what presently exists, program attendance, and the number of alternative languages these services and programs are offered in. Multi-lingual programs are especially important within a city like Toronto where there is a sizable immigrant population. An independent study reaching out to primary caregivers whose first language is not English should be done to ensure that their needs and the needs of their child are being met. These individuals could be encountering issues within the system that we are not yet aware of.

Though work-family literature has done a number of studies on the employment supports needed by primary caregivers of children with special needs, there has not been a policy study done of the employment standards that are maintained within Ontario. As of now, work flexibility for those who have special needs is not mandated in the Ontario Employment Standards Act (Employment Standards Act, 2000), instead it is left up to the discretion of the employer. However, anecdotal evidence suggests that though more employers are adopting some version of flexible working hours, this practice is not consistent. It would be worthwhile to conduct a study looking at how employers accommodate employees who have children with special needs and require more flexible working hours. Accumulating hard data on what is presently needed and what is presently being done for the working primary caregivers would allow for an informed policy proposal to be made.
The possible studies that could be done to assist this population are countless, which speaks to the amount of work that still needs to be done in order to support primary caregivers. However, based on the current findings, it appears that the majority of this work is systemic. Although caregivers appreciate and benefit from individual support from professionals, friends, and family, they would not need as much support if they did not feel that the system was failing them. Regardless of the direction future research takes, it should have the primary caregivers and their children at the forefront when deciding on research topics and structuring research design.

**Reflexivity**

I have been doing some form of research for almost a decade now. However, I have never had the opportunity to conduct my own research. Arguably, I never knew what I wanted to research until recently. My research question came from working in Autism research prior to starting my Master of Social Work program, and from perpetually hearing the frustrations of primary caregivers. Their frustrations typically revolved around feeling isolated and lost within the service system. However, I recognized that though I may be familiar with the field of Autism, it does not mean I know what it is like to access and receive services, as I am not a primary caregiver of a child with ASD. Nothing can compare to first-hand experience.

**Experience of the Research Process**

Determining how to frame the research question and research design was not as difficult as carrying out the interviews with the participants. At the end of each interview, I wrote down the feelings that I felt during the interview, and some key points that participants brought up. The feelings that I felt during the interviews included:
Overwhelmed
Frustrated
Sad
Angry
Resigned
Strength

My response to participants’ feelings was empathy, and indignation about the number of obstacles that they have encountered. I also had great admiration for their resilience. The key points that I highlighted in the field notes were what I referred to during my analysis, and helped establish the final themes and sub-themes. These were:

- Service system
- Care coordination
- Public transportation
- Feelings of kinship and community with those who are also caregivers
- Importance of possessing knowledge about ASD
- Waitlists
- Work-family balance

I believe it is important to acknowledge that throughout the research process as the primary investigator, I was in a position of power to determine which elements of the interview were relevant. While conducting interviews, through analysis, and even when writing the final product, I decided what to emphasize and what to include. For instance, the interviews were designed to be semi-structured, allowing for variability in the participant responses. This means that while interviewing, I had to maintain a balance between guiding the interview and ensuring
that I was not leading participants’ responses. This became more difficult as I continued to interview participants, since I could compare the responses to those of previous participants’ to what the current participant was saying.

Outside of being cognizant of not leading my participants during the interview, I also had to ensure that while interviewing participants, I did not victimize them. Being an able female with no dependents, I am in a position where I am only required to care for myself. When I hear what participants had to go through in order to care for their child, I had to make sure I did not feel sorry for them. Participants were not looking for pity. The participants are strong, able, resourceful individuals who just happen to live under different life circumstances than I do. Pitying them would not be fair to them and would undermine their experiences.

Ensuring that I was aware of biases became even more important while analyzing the interview transcripts. Having only done thematic analyses informally and on other people’s, projects, it was a different experience analyzing my own work and having much more invested in it. I was very nervous about misrepresenting the experiences of the primary caregivers. I tried to take care of maintaining objectivity and not leaning towards themes that would fit nicely within a narrative.

With this in mind, the analysis of the transcripts took much longer than anticipated to ensure that each individual narrative was properly represented. For that reason, I was relieved that I followed the analytical process outlined by the narrative framework. Even with the framework, I found qualitative analysis much more interpretive than what I was used to, and had to check my bias periodically.
Before and After

I have had previous experience in the ASD field. I was reasonably familiar with the issues that children with ASD and their families encounter. However, the research I was involved in was not about services and supports, and the information I had was anecdotal and sporadic. Going into the research, I believed I was going to get a lot more information about individual services and supports, and what may or may not work for primary caregivers. Furthermore, though I was aware that the service system was complicated and hard to navigate, I did not realize nor process the amount of stress that this may put on primary caregivers. This may have been due to the context in which I previously spoke to primary caregivers - that is, with respect to their child and not themselves.

After completing this study, I now realize that though primary caregivers need individual support from professionals, friends, and family, what they need more is to make sense of the system that they are going to be part of on behalf of their child. An extensive study has been conducted on the *Primary Care of Adults with Developmental Disabilities in Ontario* in 2013 by the Centre of Addictions and Mental Health (CAMH), Heath Care Access Research and Developmental Disabilities (H-CARDD), and Institute for Clinical Evaluative Sciences (ICES). However, to date, no study has been conducted on developmental services for those accessing services under the age of 18. Until a similar project is done for child and youth development services, it is very hard to determine the true state of child and youth development services.

Since completing this study, I have empathy for the families that have to depend on the system, and think about how to alleviate the stress that they feel. A change that I believe would have a great impact is updating employment standards to require employers to accommodate the needs of employees with family members with special needs. Creating a standard where a degree
of work flexibility is mandated for this population would benefit every single working primary
caregiver, regardless of socio-economic status or culture. Other changes that are needed
according to the systemic concerns outlined by the participants would require restructuring the
entire development service sector, and it would take years to implement the changes.

I have come out of this research very interested in developmental service policy and wish
to gain a greater understanding on how programs and services are implemented throughout
Ontario. In the meantime, examining how to support primary caregivers of children with ASD
within the current system is also of great interest. It could be years, if ever, before system change
actually occurs, and for good reason. If the developmental service system is indeed going to be
restructured to better serve the population, it should be done properly. Proper restructuring would
require multiple consultations from various agencies and organizations and the population itself.
Furthermore, this re-construction would require multi-ministry collaboration. Though such
system restructuring takes time, primary caregivers still need to be helped in supporting their
child.

Conclusion

This study investigated what primary caregivers of children with ASD need to feel
supported. On an individual level, what was found was that knowledge about ASD and the
ability to listen are equally important for participants. Though possessing both traits is ideal, it is
not an expectation. Participants did feel more supported when professionals had knowledge
about ASD, and when their friends and family possessed the ability to listen.

The larger findings of the study came in the form of identifying service and system gaps.
Participants highlighted five systemic issues that cause them the most stress as primary
caregivers. These are language and physical accessibility; care coordination/service navigation;
waitlists; program structure; and need for work flexibility. Though all issues are problematic, the discussion around care coordination/service navigation and waitlists indicate that the system is broken for those who want to access it and something needs to be done.

Determining what is to be done is overwhelming for a number of reasons. The first reason being that the needs of every child are slightly different, and the reason second being that the system is structured slightly differently in every region. Lastly, no reliable research or data presently exists about the state of the system in Ontario, much less in the city of Toronto. Additionally, system change inevitably takes a long time, and support needs to be provided in the meantime. However, no support presently exists that is able to address all the issues presented by the participants.

With this in mind, the suggestion from this study is to apply the Community of Practice model to situate the primary caregivers as experts and mobilize them to support each other in the meantime. As a collective, they possess as much knowledge about the service system as any professional and can assist each other in areas of service navigation, funding, and even referrals. Mobilizing them online would increase accessibility and time flexibility for those who find it hard to find babysitters or do not have easy transportation access.

When it comes to supporting primary caregivers, providing support is essential since stress does not only affect the individual, but also the child for whom they are caring. Though this study was framed to be exploratory, it does still highlight that finding support requires not only a thorough understanding of the system, but a degree of resourcefulness and creativity.
Appendices

Appendix A: Informed Consent Form

INFORMED CONSENT STATEMENT

for expedited and full review studies

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT


Principal Investigator: Nicole Siron MSW Student

Advisor: Magnus Mfoafo-M’Carthy Assistant Professor at the Faculty of Social Work

You are invited to participate in a research study. The purpose of this study is to explore ways of improving the support system available to primary caregivers of children with Autism Spectrum Disorder in the Toronto region. Through this study, we can begin to find out if the existing resources/services (e.g. programs, support groups, seminars) are meeting the needs of the people they serve.

INFORMATION

We are looking for primary caregivers of children between the ages of 4-10 years with a diagnosis of ASD who live in Toronto.

If you decide to participate, you will be asked to fill out a brief survey that collects basic information about you (e.g. age, education, marital status) and then to participate in an interview. The interview will take approximately 60 minutes and will involve a discussion about your experiences as a primary caregiver of a child with ASD. It will ask about what it has been like for you to access services and supports within the City of Toronto. In addition, your opinion about existing resources/supports and what resources/supports you might wish to have will be asked for.

Interviews will be recorded using a voice recorder for later transcription. All interviews and related materials will be kept confidential to ensure anonymity.

The information provided will only be used by the researches stated on this consent. Outside researchers will only be granted access to the information you provide if they supply an official consent form from you stating that they have been granted permission.

RISKS

We recognize that discussing the experience of supports with relation to your child’s diagnosis could be stressful and emotionally draining and you can end the interview at any point.
BENEFITS

There are no direct benefits to you or your family for participating in this study. Participation in this study will set the foundation for future studies that are interested in looking at primary caregiver supports within Toronto.

CONFIDENTIALITY

Confidentiality will be protected by promptly removing all identifying information and assigning a participant number. The list of participant numbers and the corresponding participants will be kept on a password protected document on a secure drive. Data collected from this study will be stored in a locked file cabinet in the Faculty of Social Work at Wilfred Laurier University. Data will be kept for 5 years, after which time all data will be shredded and electronically deleted. Participant information will only be accessible by the primary investigator and the advisor that have been stated. Confidentiality will only be broken if there is suspicion of harm to self or others (including the child). Names of participants will never be identifiable within any report, presentation or discussion that may result from this study.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,* ) you may contact the researcher, Nicole Siron, at 120 Duke Street W, Kitchener, ON, N2H 3W8 , and siro8130@mylaurier.ca . This project has been reviewed and approved by the University Research Ethics Board, as well as the SPC REB. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, at (519) 884-1970 or rbasso@wlu.ca or Dr. Barry Isaacs, Chair, SPC Research Ethics Board, at barry.isaacs@surreyplace.on.ca.

PARTICIPATION

Your participation in this study is voluntary. Your decision to participate, or not, will have no effect on the services you or your child receive. As a participant, you are also able to refuse to answer any question you are asked as part of the research. If you decide to participate, you may still end your participation from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, every attempt will be made to remove your data from the study and have it destroyed. You have the right to refuse to answer any question(s)/procedure(s) you choose.

PROCESS

Results will be gathered based on interviews. Interviews will be subsequently transcribed and analyzed. Qualitative coding will be used to establish themes which will inform the written report.

After the transcription of the interview has been completed, a copy of the transcribed interview will be sent by email to the participant to be reviewed. Please be aware that this email may not be secure. Information from the interview will not be used until you approve of the interview transcript. Email confirmation by the participant will be kept on file by the researcher.

FEEDBACK AND PUBLICATION

Research results will be published in the student’s Masters dissertation as part of her fulfillment for her
Masters of Social Work program.

Results of the research will only be provided after the completion of the Masters dissertation in April 2015. Please indicate if you wish to receive a report on the results by checking the appropriate box.

☐ YES  ☐ NO

CONSENT

By signing this form, I agree that:

1. You have explained this study to me. You have answered all my questions.

2. You have explained the possible harms and benefits (if any) of this study.

3. I understand I have the right to refuse to participate in this study. I also have the right to leave the study at any time. My decision about participating in this study will not affect any services that I or my child may be accessing at Surrey Place Centre or any other organization.

4. I am free now, and in the future, to ask questions about the study.

5. I know this study involves a short survey and an interview about my experiences accessing supports and services.

6. I know that the investigator and her supervisor will have access to any information that I provide on behalf of this study.

7. I understand that quotes and accounts from my interview may be used, but my name will never be used.

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant’s signature____________________________________  Date ____________________

Investigator's signature____________________________________  Date ____________________

I understand and give permission for the researchers to use quotes and accounts from my interview if they feel that it is appropriate in their subsequent publications.

Participant’s signature____________________________________  Date ____________________
Appendix B: Interview Protocol

Time of Interview:
Date:
Place:
Interviewer:
Interviewee:

Interview Questions

Diagnosis
1) What was your experience of your process of diagnosis?
   a. Did you feel supported during this process?
   b. If so, in what way?
   c. If not, in what way?

Informal Supports
1) Can you describe your present family and friend support system?
   a. If so, in what ways do they provide you support? (E.g. child care, emotional support, etc.)

Formal Supports/Services/Programs
1) Presently, are you accessing any formal supports that are specific to primary caregivers?
   a. If so, what are they and what is your experience of them?
   b. If not, would you feel such supports would be beneficial? And, how would you envision them?
2) What formal supports (services and programs) are you accessing in relation to your child with ASD?
3) If so, what is your experience of them? (E.g. accessibility, quality, variety, etc.)
4) What supports (services and programs) would you feel would be beneficial?

Daily Life
1) As a primary caregiver can you tell me about the challenges of taking care of a child with ASD
   a. What experiences about being a primary caregiver of a child with ASD been enriching for you?
2) What is helping you overcome these challenges
   a. If so, which supports in particular would you say are the most beneficial? And, why?
   b. If not, what would need to change so that you would feel better supports as a primary caregiver of a child with ASD?
Appendix C: Demographic Survey

Demographic Information

Primary Caregiver Information

Age:
Gender:
Ethnicity:
Education level:
Marital status:
Employment status:

Family Information

Number of children in the family:
Number of children with ASD in the family:

Child with ASD Information

Child’s official diagnosis:
Age of ASD diagnosis:
Present age of child with ASD:
Is the child with ASD attending school:
Appendix D: Research Flyer

Examining the Supports for Primary Caregivers of Children with Autism Spectrum Disorder

We need help from primary caregivers of children (4-10 years old) with Autism Spectrum Disorder (ASD) who live in the Toronto region

We want to hear about your experience as a primary caregiver!

What the study is about?

We are exploring the following:

- What it is like for you to access services and supports in the city of Toronto
- What your opinion is of the existing resources/supports
- What resources/supports do you envision having available to you

What is involved if you participate in the study?

Participants will be required to:

- Fill out a short demographic survey
- Participate in a 60-90minute interview talking about the primary caregiver experience of a child with ASD

Who to contact if you are interested?

If you are interested in participating in this study, please contact Nicole Siron at siro8130@mylaurier.ca

THIS STUDY HAS RECEIVED ETHICS CLEARANCE FROM THE RESEARCH ETHICS BOARD AT WILFRID LAURIER UNIVERSITY, IT CAN BE FOUND UNDER FILE# 4074
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