A Comparison of Parenting Daily Hassles in Parents of Children with Autism and Typically Developing Children

by

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A thesis submitted in conformity with the requirements for the degree of Master of Arts
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Abstract

Parenting a child with autism spectrum disorder (ASD) is known to be highly stressful and has been reported to be more difficult than parenting children with different types of disability, or with no disability; however, the daily hassles that contribute to the increased stress for this specific group have not been studied systematically. The main goal of this research was to determine what areas of daily strain are most prevalent in the lives of parents with young children with autism. Participants were 16 parents of a child with ASD and 16 parents of a child without ASD (child age range: 47-78 months). Parenting daily hassles and demographic features were assessed using questionnaires. We investigated which specific daily hassles uniquely characterize the lives of parents of children with ASD in comparison to the hassles characterizing the lives of parents of typically developing children. Parents of children with ASD experienced greater levels, frequency, and intensity of daily hassles, particularly in relation to hassles associated with diagnostic criteria of ASD including social communication difficulties and restricted and repetitive patterns of behaviour. Further, additional factors such as marital status influenced parenting daily hassles, with parents of children with ASD experiencing greater levels of daily hassles when raising a child as a single parent. Determining the aspects of daily life that are most difficult for parents of children with ASD can inform policy priorities and decisions about the types of supports would be most helpful.
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## Table of Contents

Abstract ........................................................................................................... ii
Acknowledgements ...................................................................................... iii
Table of Contents ........................................................................................ iv
List of Tables .................................................................................................. v
List of Appendices ........................................................................................ vi
Introduction .................................................................................................... 1
Method ............................................................................................................ 13
Results ........................................................................................................... 17
Discussion ...................................................................................................... 22
References ..................................................................................................... 40
Tables .............................................................................................................. 45
Appendices .................................................................................................... 47
List of Tables

Table 1: Frequency and Intensity of Daily Hassles Reported by Mothers of Children with and without ASD

Table 2: Differences in Specific Hassles Reported by Mothers of Children with and without ASD
List of Appendices

Appendix A: Informed Consent to Participate in a Research Study

Appendix B: Demographic Questionnaire

Appendix C: Early Childhood Parenting Daily Hassles Questionnaire

Appendix D: Telephone Recruitment Script

Appendix E: Regular Mail and Email Recruitment Letter
Introduction

The present study investigated which areas of daily hassles are most prevalent in the lives of parents with young children with autism spectrum disorder (ASD) as compared to parents of typically developing children. Parenting daily hassles are viewed as the recurring demands associated with raising a young child (Crnic & Greenberg, 1990). Parents of children with ASD have reported higher levels parenting stress than parents of typically developing children; however, the daily tasks that contribute to the increased feelings of stress for this specific group have not been studied systematically. Understanding the specific daily hassles faced by parents raising children with ASD is important for developing appropriate programs and services, and can inform decisions about what types of supports would be most helpful. As the prevalence of ASD increase, gaining knowledge about how this disorder affects parents and families is of critical importance to reduce the risk of negative outcomes for children and parents.

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a heterogeneous disorder comprising deficits in social communication and interactions, and restricted, repetitive behaviours, interests, or activities (American Psychological Association, 2013). ASD is approximately 4.5 times more common among boys than girls (Centers for Disease Control and Prevention, 2016). Approximately 1 in 68 children have been identified with ASD, and the disorder appears to occur in all racial, ethnic, and socioeconomic groups (Centers for Disease Control and Prevention, 2016). Clinical presentation of ASD can include behaviours such as failure to initiate or respond to social interactions, poorly integrated verbal and nonverbal communication, insistence on sameness and inflexible adherence to routines, and hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (American Psychological Association,
2013).

**Parenting Stress**

There are many responsibilities that occur in the context of being a parent, including the required activities involved in raising a child, the responsibility of managing the emotional and physical needs of a child, and the adaptation to a child’s ever-changing needs throughout development. It is no surprise that the responsibility of being a parent is associated with stress.

Parenting stress formally occurs when parents experience discord between actual parental demands and their perceived availability of resources to address those demands (Walerius et al., 2016). The demands of parenthood are vast and can include knowledge about and competence with the daily tasks associated with parenting (e.g., changing diapers, feeding infants, dealing with temper tantrums; Deater-Deckard, 1998). Deater-Deckard (1998) defined parenting stress as the “aversive psychological reaction to the demands of being a parent,” where stress is represented by the task demands of parenting, the parent’s psychological well-being and behaviour, the qualities of the parent-child relationship, and the child’s psychosocial adjustment.

Parents experiencing parenting stress may feel negatively towards the child or the self and these feelings are directly attributable to the demands of parenthood (Deater-Deckard, 1998).

The dominant model of parenting stress references two major domains of stress: the child domain, which arises from child characteristics, and the parent domain, which is more affected by parental functioning. Total stress is the combination of parent- and child-based stress (Abidin, 1995; Theule, Wiener, Tannock, & Jenkins, 2012). Parents who have less knowledge, less perceived competence, and less emotional and physical support from family, friends, and partners, or have a behaviourally difficult child are likely to view the parenting experience as more difficult and experience more stress associated with parenting (Deater-Deckard, 1998).
Further, parental depression is a strong correlate of parenting stress, with parents who are struggling with their own emotional difficulties having fewer coping resources and feeling more stressed by their children’s challenging behaviours (Davis & Carter, 2008). In regard to child characteristics, having a child with a more difficult temperament (e.g., frequent fearful or angry mood, quick to react negatively, difficulty calming down) is associated with higher levels of parent stress; however, this relationship is complex, with parental reactions to child temperament influencing parental stress (Deater-Deckard, 2004). In addition, demographic variables such as low level of education, single parenthood, minority ethnic background, and economic hardship have all been linked to increased stress in parents’ lives (Östberg & Hagekull, 2013). In general studies of parenting stress, researchers have found that a number of demographic factors play a role in the levels of stress experienced by parents. Past research exploring sex differences in parenting stress has shown mixed results, with mothers often showing greater stress than fathers; however, in households where mothers and fathers shared child care, both parents reported lower levels of parent stress (Deater-Deckard & Scarr, 1996). Further, studies reporting higher levels of parenting stress for mothers have often been based on clinical samples of children with chronic illnesses or behavioural adjustment problems; parenting stress in families with adequate resources may be qualitatively different from stress in families coping with serious child problems, resulting in few parent sex differences (Hauenstein, 1990). Higher levels of parenting stress have also been associated with lower family income and lower levels of parental education (Deater-Deckard & Scarr, 1996). While child age has been shown to correlate with parenting stress (e.g., parents of older children report less parental stress), child sex has not been shown to be associated with parent stress (Deater-Deckard & Scarr, 1996).

Although parenting stress is considered to be a normal experience, elevated levels of
parenting stress may affect the parent-child relationship and have a negative impact on parenting practices (Theule et al., 2012). For example, higher levels of parenting stress are believed to impact the implementation of interventions, such that parents experiencing high parenting stress are less able to engage in and implement behavioural parent training interventions (Walerius et al., 2016; Walsh et al., 2013). For these reasons, it is important to better understand the causes of parenting stress so that appropriate interventions can be implemented with clinical populations.

**Parenting Stress in Atypically Developing Populations**

Parents of children who are disabled, impaired, or critically ill experience higher levels of parenting stress when compared to parents of healthy, typically developing children (Deater-Deckard, 2004). Parents of children who have more disabling, long-term conditions show more signs of chronic parenting stress, as do parents whose children have more behavioural and emotional problems (Deater-Deckard, 2004). In regards to parenting stress, problem behaviours from the child have been shown to be the primary predictor of parent stress, and can result in increased stress for family members, isolation from the community, and exclusion of the child and/or family from educational settings and social relationships (Walsh et al., 2013). In particular, problem behaviours can increase the level of difficulty associated with completing daily caregiving tasks such as bathing, feeding, and supervising the child (Walsh et al., 2013). Further, for some families of children with illnesses or disabilities, parenting stress may be related to financial difficulties, inadequate social support, increases in child problem behaviours or child emotional disturbances or problems with self-control (Deater-Deckard, 2004). In addition, individual differences in children’s cognitive, language, and social-behavioural skills have been associated with parental stress, with higher impairments associated with increased stress (Deater-Deckard, 2004).
Further research has demonstrated that parents of children with elevated internalizing and externalizing problem scores report more stress than those with children with non-elevated scores (Nachshen et al., 2005). For these families, the overall level of dysfunction or impairment is associated with the degree of parenting stress experienced in the family (Deater-Deckard, 2004). Parents of children with difficulties such as emotion dysregulation and ADHD tend to experience significantly greater parenting stress than parents of typically developing children (Walerius, Fogleman, & Rosen, 2016; Theule, 2012). Specifically, parents of children with ADHD have reported more frequent and intense levels of daily parenting hassles than parents of children without ADHD (Walerius et al., 2016). Further, the negative emotional lability of children with ADHD significantly predicted the intensity (i.e., how much stress) of daily parenting hassles in the ADHD group (Walerius et al., 2016). More generally, the research presented by Walerius et al. (2016) suggests that negative emotional lability in children predicts more intense stress from daily parenting hassles, regardless of ADHD status. Furthermore, ADHD was not found to be associated with more parenting stress than other clinical disorders, suggesting that parent stress may result from factors common to having a child identified with any clinical disorder (Theule et al., 2012).

**Parenting Stress Associated with Raising a Child with ASD**

The topic of parenting stress has been well-researched in families of children with ASD, with numerous studies demonstrating that parents of children with ASD tend to experience higher levels of stress when compared to parents of typically developing children or parents of children with other disabilities (Davis & Carter, 2008; Myers et al., 2009; Rutgers et al., 2007; Walsh et al., 2013). Further, parenting a child with ASD has been reported to be more difficult than parenting a child with different types of disability or no disability at all (Harper et al., 2013).
For example, children with ASD tend to exhibit a greater intensity of challenging behaviour than children with Down syndrome, thereby leading to higher levels of parenting stress for the parents of children with ASD (Rutgers et al., 2007). The finding that parents of children with ASD report increased levels of parenting stress is supported by studies using a wide variety of measurement tools (Davis & Carter, 2008), including global estimates of parenting stress (Sharpley et al., 1997), measures designed for use with parents of children with disabilities (Koegel et al., 1992) and measures designed for use with the general population such as the Parenting Stress Index (Dumas et al., 1991).

Three of the most stressful factors related to parenting a child with ASD are the permanence of the condition, the poor level of acceptance of typical “autistic” behaviours by society and other family members, and low levels of social support (Sharpley et al., 1997). Mothers of children with ASD have been shown to experience a higher level of stress in activities involving social contact, such as shopping or taking trips (Koegel et al., 1992). Additionally, mothers have been shown to suffer higher levels of anxiety and depression than fathers of children with ASD, something which may be explained by the fact that mothers typically assume greater responsibility for the day-to-day care of children (Hosley & Montemayor, 1997; Parke, 2000). Other factors that have been shown to exacerbate the level of stress experienced by these parents are the age of the child, with parents of older children showing higher levels of stress, and the age of diagnosis, with a significant relationship between age of diagnosis and level of depression in parents (Sharpley et al., 1997). In ASD populations, factors including the severity of behavioural disturbance shown by the child with ASD, the gender and the age of the parent, and levels of social support received by the parent have been associated with the higher levels psychological distress experienced by a parent raising a child
with ASD (Bromley, Hare, Davison, & Emerson, 2004).

As found in qualitative studies, parents of children with ASD report feeling: “stressed out”, “exhausted”, “burned out”, and “at their wits end” (Harper et al., 2013). Parents of children with ASD report sources of stress that include inappropriate and unpredictable behaviour of their child and concerns about their child’s future and educational needs (Harper et al., 2013). In addition, there are higher demands placed on parents of children with ASD for coordinating services (Quintero & McIntyre, 2010), which often involve a range of professionals from different disciplines and sectors, as well as advocating for a variety of supports in school. Moreover, their child’s impaired communication, inappropriate social engagement, and challenging behaviours are all considered to be stressors mainly felt by parents of children with ASD (Harper et al., 2013).

A qualitative study completed by Myers, Mackintosh, and Goin-Kochel (2009) explored how raising a child with ASD affected parents’ lives. Specifically, parents of children with ASD reported difficulties in being able to find appropriate child care, dealing with school staff, and coping with challenging behavioural issues. For example, one parent stated that the school called her almost every day because of her child’s behaviour issues. In addition, parents report fearing for their child’s safety, due to the child’s poor awareness of danger and limited understanding of safety protocols (Myers et al., 2009). Other parents reported that their social networks had reduced in size, and that support from friends and family often lessened because of their child’s behaviours. Moreover, children with ASD frequently exhibit disruptive and hard-to-manage behaviours, and parents often feel trapped at home, for fear of their child causing a scene or getting injured in a public place (Myers et al., 2009). Behaviours such as regulatory problems (e.g., eating, sleeping, emotion regulation) may be associated with parenting stress in parents of
children with ASD; however, little research has examined the relationship between specific child behaviours and parenting stress (Davis & Carter, 2008). In a study examining the predictors of parenting stress for mothers and fathers of young children with ASD (ages 18-33 months), the most consistent predictors of stress were the child’s delays and deficits in social skills. Further, behaviour problems including difficulty with self-regulation skills (e.g., eating, sleeping, and emotion regulation) and externalizing behaviours that are not always specific to ASD were also associated with parental stress (Davis & Carter, 2008). Although some studies have found that ASD-related atypical behaviours and communication deficits were predictive of stress in parents of older children with ASD, other studies have yielded less conclusive results (Davis and Carter, 2008). This finding suggests that parenting stress associated with raising children with ASD may differ based on the individual behaviours of the child and that parents may face different challenges at different life stages.

**Parenting Daily Hassles**

Early research viewed stress as resulting from major life changes or life-events, with the idea being that the accumulation of life events should relate to health and well-being and that accumulating major life events was a rational way of assessing stress (Kanner, Coyne, Schaefer, & Lazarus, 1981). In the past 30 years, a new stress perspective has developed, and with it a view of stress in which minor or everyday events or “hassles” contribute to overall levels of stress (Chamberlain & Zika, 1990). Lazarus (1984) initially proposed an alternative measure of stressors that focused on everyday events or hassles, which were conceptualized as “experiences and conditions of daily living that have been appraised as salient and harmful or threatening to the endorser’s well-being.” The “hassles” perspective views stress within a relational framework as a product of environmental events and appraisal of personal significance by the individuals
involved. These minor events reflect the everyday concerns that are felt to be significant to an individual’s well-being (Chamberlain & Zika, 1990). Hassles are considered to be irritating and frustrating demands that characterize interactions with the environment, including events such as losing keys, traffic jams, arguments, or family concerns (Kanner et al., 1981).

Several studies have examined the nature of hassles, including the differences in hassles endorsed most frequently by students, middle-aged adults, and health professionals (Kanner et al., 1981). Each of these groups reported concerns of appropriate relevance to their life stage, with older and younger people reporting different patterns of hassles. In combination, these results suggest that the ‘minor-events’ approach does identify concerns relevant to the personal and social situations of individuals (Lazarus, 1984) that may be informative beyond an individual’s responses to major life events. In addition, research supports the idea that minor daily hassles measures are better predictors of psychological distress and physical and mental health than life-event measures (Chamberlain & Zika, 1990; Kanner et al., 1981). For example, one study looked at how daily hassles related to mental health and well-being outcomes in mothers and found that hassles were highly associated with mental health and well-being, whereas life events had relatively low associations with these outcomes (Chamberlain & Zika, 1990).

Expanding on the “hassles” stress perspective, Crnic and Greenberg (1990) presented a model of parenting daily hassles in which parenting stress was conceptualized within a minor event perspective to address the everyday frustrations that accompany childrearing. Parenting hassles were categorized as the minor, but frequent, day-to-day challenges of completing basic parenting tasks and managing child behaviours (Walerius et al., 2016). Subsequent research in the area of parenting daily hassles has supported the validity of parenting daily hassles as a
meaningful stress context for families (Crnic, Gaze, & Hoffman, 2005), although other researchers have found that daily hassles are better predictors of parent stress and functioning than major life stressors (Walsh et al., 2013; Kanner et al., 1981).

In previous studies of parenting hassles, levels of parenting daily hassles differed among certain groups of parents, depending on demographic factors. Bell (2011) determined that significant differences in reported daily hassles were found for parent gender, language, and employment status. These results indicated that male parents experienced higher levels of daily hassles than female parents, parents who spoke English as a second language experienced higher levels of daily hassles, and parents who were employed full-time or enrolled as a student experienced higher levels of daily hassles than parents who worked part-time or were unemployed or stay-at-home parents (Bell, 2011). Conversely, earlier research examining gender differences in reported parent hassles and stress generally demonstrated mixed and inconclusive results, with only small differences between mothers’ and fathers’ reported hassles (Arimura, 2008). Further research is required to examine how parent demographic factors have an impact on daily hassles and parent stress.

**Rationale for the Current Study**

Research indicating that raising a child with ASD can be a highly stressful experience is helpful in understanding that the parents of children with ASD may be a risk for higher rates of psychological distress, and likely need greater parenting support than parents raising typically developing children. Nonetheless, the available research fails to capture the daily details and incidents that contribute to the increased stress and difficulty of raising a child with ASD (Myers et al., 2009). At this stage in ASD research, there seems to be a clear understanding that parents of children with ASD tend to experience more parental stress than parents of typically
developing children. The majority of research on stress related to raising a child with ASD has focused on overarching differences, such as that parents of children with ASD show higher levels of daily stress than parents of typically developing children and children with other disorders.

Conversely, little research has focused on breaking down parental stress into its smaller components and examining whether there are specific kinds of stressors distinctive to each population. Previous research has recommended conducting a comparison study of daily hassles in families of children with ASD and typically developing children to determine if there are specific kinds of stressors more common in each population (Walsh et al., 2013). In one study, mothers of children with ASD reported significantly more daily hassles, life stress, and depression than mothers without a child with ASD (Quintero & McIntyre, 2010). In this study, the researchers reported significant differences in total Parenting Daily Hassles (PDH) scores between mothers of children with ASD and mothers of typically developing children; however, the specific nature of the daily tasks that were viewed as increased hassles for mothers of children with ASD was not explored (Quintero & McIntyre, 2010).

Previous research on the stress experienced by parents raising children with disabilities has been limited in two major areas. First, research has failed to conceptualize and measure specific areas of parenting stress. Second, research has not always used study designs that include comparison groups of typically developing children (Noh, Dumas, Wolf, & Fisman, 1987). Further, in this research area, no one has specifically looked at the unique stressors faced by parents raising children with ASD in the early childhood stages, and how their interactions with early childhood services (e.g., kindergarten, day care) contribute to increased daily stress.

Objective of the Present Study
Using the Early Childhood Parenting Daily Hassles Questionnaire (Bell, 2011), this study aims to examine how parents of young children with ASD rate the intensity and frequency of daily hassles as compared to parents of typically developing children. The use of this scale will allow for a more in-depth look at which specific aspects of parenting are more stressful when the child in question has a diagnosis of ASD. Developing a better understanding of the aspects of daily life that are most difficult for parents of children with ASD will allow for more specific recommendations regarding what areas of daily life parents find most challenging on a daily basis and the kinds of support parents would find most beneficial.

Therefore, this study was guided by three main objectives. The first objective was to compare the intensity and frequency of daily hassles experienced by parents of children with ASD and parents of children without ASD. It was hypothesized that parents of children with ASD would experience significantly higher frequency and intensity of daily hassles than parents of typically developing children. The second aim was to determine whether the pattern of daily hassles experienced by parents of children with ASD was related to the symptomatology of ASD. It was hypothesized that daily hassles related to characteristics associated with the DSM-5 diagnostic criteria for ASD would be experienced more frequently and intensely by parents of children with ASD than by parents of typically developing children. In addition, within the ASD group, daily hassles related to characteristics of ASD were expected to be experienced more frequently and intensely than daily hassles not directly related to symptoms of ASD. Finally, this study attempted to determine if there were characteristics of the parent of a child with ASD or the child with ASD that impacted daily hassles reported by parents. It was hypothesized that features likely to contribute to increased stress in the home (e.g., severe ASD symptomatology, being a single parent, low family income) would increase the frequency and intensity of daily
hassles experienced by parents.

Method

Participants

Parents of children with ASD were recruited through databases of families interested in participating in future research studies (e.g., POND database, Infant Sibling Study database, Autism Treatment Network database) at Holland Bloorview’s Autism Research Centre. Approximately 100 parents were contacted by the researcher and were invited to participate in this study, with 22 parents agreeing to participate and 18 returning their completed surveys. Two of the returned surveys were excluded from analyses because the child exceeded the age limit of the current study. Data from the typically developing comparison group were obtained from a database held by Dr. Janette Pelletier through the Jackman Institute of Child Study at the University of Toronto. These data were collected as part of a longitudinal study on the effects of full-day kindergarten on child outcomes. A fixed variable matching procedure was used to select a subset of children from the comparison group database to obtain a sample of appropriately-matched participants for the children with ASD. Children from the clinical sample (i.e., children with ASD) and the comparison group were matched on a 1:1 ratio, based on sex and age (in months), with the age of matching participants being within 3 months of each other. In two cases, children with ASD were matched with typically developing children within 6 months of their age.

The sample consisted of 16 parents (100% mothers) of a child with ASD (14 males and 2 females) and 16 parents (100% mothers) of typically developing children (14 males and 2 females). All children with ASD were between the ages of 47 months and 78 months and had attended at least four months of kindergarten at the time of recruitment (January 2017). At the
completion of the data collection phase (July 2017), children with ASD were between 57 and 83 months of age. Children in the previously collected comparison group data set were between 51 and 76 months. In the ASD group, 12 children were identified by parents as being diagnosed with autism spectrum disorder (ASD), 1 with high functioning autism, 2 with severe autism, and 1 with autism. Children in the comparison group were not identified with any mental health diagnoses.

Thirty-one mothers (97%; $n_{ASD} = 16$) provided information on their own level of education. Over half of the participating parents ($n = 18; 58\%$) had completed at least some post-secondary education ($n_{ASD} = 15$). Thirty-one mothers reported on their marital status ($n_{ASD} = 15$), with 27 reporting being married or common-law ($n_{ASD} = 13$), 1 reporting being separated or divorced ($n_{ASD} = 1$), and 3 reporting never being married or living with a partner ($n_{ASD} = 1$). Twenty-nine mothers ($n_{ASD} = 15$) reported on their employment status, with 16 reporting they had a full-time paid job ($n_{ASD} = 6$), 5 reporting they had a part-time paid job ($n_{ASD} = 2$), 7 reporting being a stay-at-home parent ($n_{ASD} = 5$), and 1 reporting being unemployed ($n_{ASD} = 0$). A 2X2 chi-square analysis revealed a significant association between educational attainment and group, $\chi^2 (1) = 17.29, p < .01$, with 93.8% of parents of children with ASD versus 20% of parents of typically developing children reporting they had attended some form of post-secondary education. Separate 2X2 chi-square analyses failed to show group differences in maternal marital status, $\chi^2 (3) = 2.30, p > .05$, or in self-reported employment status, $\chi^2 (1) = 2.76, p > .05$.

**Measures**

**Demographic questionnaire.** Parents of children with ASD were asked to complete a demographic questionnaire that was based on questionnaires utilized by previous studies in the Autism Research Centre, and asked questions similar to those answered by parents in the
typically developing comparison group (e.g., parental education, employment and marital status). In addition, parents were asked to check off symptoms relating to the severity of their child’s ASD (i.e., verbal or non-verbal; able/unable to complete self-care tasks), whether their child attended private or public school, and to report on parental occupation, and household income (Appendix B).

**Parenting hassles scale.** The *Early Childhood Parenting Daily Hassles* (EC-PDH) scale was adapted by Arimura (2008) from the *Parenting Daily Hassles* (PDH) scale developed by Crnic and Greenberg (1990). The original scale was a 20-item measure that assesses events that routinely occur in families with children that are typically considered to be a hassle. Arimura’s (2008) adaptation was designed to measure parental perceptions about hassles specific to the early childhood context. The scale consists of items relating to typical responsibilities and tasks associated with parenting. Frequency and intensity summary scores are computed from this measure as well. The frequency score reflects the regularity of the stressors, whereas the intensity score reflects the extent of how stressful that item is to the parent. The current study used a modified version of the EC-PDH that has been expanded to include 42 items (Bell, 2011; Appendix B). Parents were asked to indicate the frequency and intensity with which they experienced each of the daily hassles items in the past month on a 5-point scale from 0 - *Never/No Hassle* to 5 (Constantly/Big Hassle). Parents also had the option of choosing the response ‘Not Applicable’ for every item, which was scored as 0 in data entry. Items representing the frequency of daily hassles were summed to create a frequency score and items representing the intensity of daily hassles were summed to create an intensity score. Total daily hassles scores were calculated by summing the frequency and intensity scores from each item on the questionnaire. Previous studies that have used this modified version of the EC-PDH have
conducted statistical analyses to determine the quality of this measure. Cronbach alpha analysis of the overall scale indicated a strong degree of internal consistency (Cronbach’s alpha = .95) suggesting that the items on the scale measure a consistent underlying construct (“hassles”) (Bell, 2011).

**Procedure**

This research was approved by the Research Ethics Boards of the University of Toronto and Holland Bloorview Kids Rehabilitation Hospital.

Recruitment of parents of children with ASD was conducted by the author of the present study. For this study, parents of children with ASD were recruited from databases of families who had indicated an interest in being contacted for future research opportunities (i.e., the POND database, the Infant Sibling Study database, the Autism Treatment Network database). Dr. Jessica Brian is the co-lead of the Autism Research Centre at Holland Bloorview, where these databases are held, and had given permission to access the databases in order to obtain participant contact information. Parents were contacted by email, regular mail, and/or telephone based on previously identified preferred methods of contact. Scripts for recruitment are included (Appendix E). Potential participants were contacted up to 4 times to request their participation in this study.

If parents indicated an interest in participating, they were mailed a package that included: the consent form, the demographics form, and the daily hassles questionnaire, with one (1) self-addressed return envelope. Parents were then instructed that if they agreed to participate they should complete and mail the questionnaires back to the researchers and keep the consent form for their personal records. Parents were invited to discuss any concerns or questions about the consent form with the researcher prior to completing the questionnaires. In order to protect
participants’ confidentiality and privacy, an implied consent procedure was used, whereby returning the completed questionnaires indicated the parents’ agreement to participate. This allowed the data being collected to remain anonymous and prevented participant responses from being identifiable when being returned. Due to the procedure of implied consent used, withdrawal of returned data was not possible, as there was no way to link a participant’s responses to their identity.

**Analytic Approach**

All statistical analyses were computed using SPSS version 21. Due to the small sample size, some categorical variables of interest with more than two categories were collapsed into two levels so that there would be a sufficient and similar number of participants in each category to complete exploratory analyses. Independent- and paired-samples $t$-tests were used to explore differences between groups and within the ASD group on continuous variables. All variables met the broad assumption of normality ($\text{skew} < |2.5|; \text{kurtosis} < |3.5|$), with the exception of two items for the comparison group and one item for the ASD group. The Bonferroni correction, a multiple-comparison correction, was used when several statistical tests were performed simultaneously (i.e., tests to examine the overall level of daily hassles, the frequency of daily hassles, and the intensity of daily hassles). The Bonferroni corrected significance level for the $p$-value was set at $0.05/\text{number of comparisons}$ (specific values are indicated below).

**Results**

**Between-Group Differences**

Independent samples $t$-tests were conducted to determine if there was a difference in the level of reported daily hassles between the parents of typically developing children and parents of children with ASD with regards to their total experience of daily hassles (i.e., a combination
of intensity and frequency of daily hassles), the intensity with which daily hassles were experienced, and the frequency with which daily hassles were experienced (Bonferroni corrected p = .05/3 = .016). Parents of children with ASD experienced significantly higher levels of daily hassles overall (M = 2.75, SD = .43) than parents of typically developing children, t (20.09) = -3.26, p = .004 (see Table 1). The 95% confidence interval for the difference of the means ranged from -1.48 to -0.33. An effect size (Cohen’s d) of .58 indicates a medium effect. In addition, parents of children with ASD reported higher intensity, t (21.75) = -3.15, p = .005, and frequency of daily hassles, t (20.98) = -3.19, p = .004, than parents of typically developing children (see Table 1).

To further investigate the nature of the parenting daily hassles (PDH) experienced by parents of children with ASD, we identified items that could be categorized as being associated with DSM-5 diagnostic criteria for ASD (American Psychological Association, 2013) and compared these items between groups. For the diagnostic criteria encompassing persistent deficits in social communication and social interaction (e.g., deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviours used for social interaction, or deficits in developing, maintaining, and understanding relationships), five items (4, 11, 17, 27, and 32) were selected from the Parenting Daily Hassles questionnaire. For the diagnostic criteria encompassing restricted, repetitive patterns of behaviour, interests, or activities (e.g., stereotyped or repetitive motor movements, use of objects, or speech, insistence on sameness, inflexible adherence to routine, ritualized patterns of verbal or nonverbal behaviour, or hyper- or hypo-sensitivity to sensory input), five different items (1, 10, 13, 18, and 19) were selected. All ten items were then compared across groups (see Table 2 for the means and standard deviations of each of the individual questionnaire items). Independent-samples t-tests were used to compare
ASD and comparison groups on each of the selected PDH items (both frequency and intensity) with a Bonferroni correction to account for a total of 20 comparisons: $p_{\text{crit}} = .05/20 = .003$. The results revealed that none of the items associated with deficits in social communication and social interaction differed in their intensity and frequency between the two groups with the conservative Bonferroni correction. Using an uncorrected $p$-value, the following trends emerged with higher ratings by parents of children with ASD: leaving their child with ASD in the morning was a significantly more intense hassle (PDH4b: $t (23.23) = 2.26, p = .034$) and knowing whether their child was happy at school was a more frequent and intense hassle (PDH32a: $t (30) = 2.28, p = .030$; PDH32b: $t (30) = 2.39, p = .023$). In addition, parents rated knowing whether their child was happy in child care as a significantly more frequent hassle (PDH27a: $t (22.49) = 2.45, p = .022$). Significant group differences did emerge for the items relating to the diagnostic criteria detailing restricted, repetitive patterns of behaviour, interests or activities: Parents of children with ASD reported having to deal with unexpected changes to their daily routine as a significantly more frequent hassle (PDH13a: $t (30) = 3.94, p < .001$), and a significantly more intense hassle (PDH13b: $t (30) = 3.11, p = .004$) than parents of typically developing children. The following trends also emerged (with an uncorrected $p$-value < .05): Parents of a child with ASD reported more frequent and intense hassles related to knowing what their child should be able to do (PDH18a: $t (30) = 2.47, p = .019$; PDH18b: $t (30) = 2.41, p = .022$), knowing if their child’s behaviour was a problem (PDH19a: $t (30) = 2.06, p = .049$; PDH19b: $t (29) = 2.41, p = .022$), and dealing with their child at the end of the day (PDH10a: $t (30) = 2.72, p = .011$; PDH10b: $t (30) = 2.96, p = .006$).

**Within-Group Differences (ASD)**

In addition to comparing specific hassles between the clinical and comparison groups, the
same ten hassles associated with characteristics of ASD were combined into a subset to compare whether parents of children with ASD rated this set of items as more frequent and intense daily hassles than the remaining items not categorized as related to features of ASD. The ten items previously selected were categorized as items that related to symptom criteria in the DSM-5, although remaining items were categorized as unrelated to ASD symptom criteria. Overall, mean parent ratings on the set of items associated with characteristics of ASD ($M = 3.17, SD = .79$) were significantly higher than parent ratings on the set of items categorized as unrelated to characteristics of ASD ($M = 2.62, SD = 1.11$), $t (15) = 4.65, p < .001$, with a 95% confidence interval of .30 to .81. The standardized effect size index, $d$, was 1.16, which indicates a large effect.

**Demographic Factors: Both Groups**

Correlational analyses were conducted to determine if the age of the child was related to the reported levels of daily hassles; no significant relationship was found for parents of typically developing children, $r (14) = .30, p = .257$ or for parents of children with ASD, $r (14) = .49, p = .082$, although a non-significant trend emerged for the latter group.

**Demographic Factors: ASD Group**

Given our finding that parents of children with ASD experience greater frequency and intensity of daily hassles than parents of typically developing children, additional analyses were conducted to examine the impact of child characteristics and parental demographic factors on experienced daily hassles within this group. For the ASD group, independent-samples $t$-tests were conducted to determine whether parents’ daily hassles total scores, and the frequency and intensity with which they were experienced significantly differed depending on the child’s (categorically defined) verbal ability and self-care skills. There were no differences in reported
levels of daily hassles based on whether the child was categorized as verbal or non-verbal for the total daily hassles score, $t(13) = -0.057, p = .96$, the frequency score, $t(13) = -0.17, p = .87$, or intensity score, $t(13) = -0.055, p = .96$. Further, there were no differences in daily hassles scores based on whether the child could complete self-care tasks independently for the total daily hassles scores, $t(12) = -1.28, p = .23$, frequency scores, $t(12) = -1.29, p = .22$, or intensity scores, $t(12) = -1.23, p = .24$. None of these effects was significant based on Bonferroni correction, where $p_{crit} = .05/3 = .016$.

Independent-samples $t$-tests were also conducted to explore the effects of marital status, household income, the educational level, and the employment status of the parent completing the questionnaire on reported daily hassles in the group with ASD. Again, the Bonferroni correction was used with the significance level set at $p < .016 (0.5/3)$ for analyses with multiple comparisons. For marital status, parents were categorized as “not married” if they reported being “single”, “never married”, or “divorced/separated”, or they were categorized as “married” if they reported being “married” or “common-law”. This system of classification resulted in only two parents in the “not married” group, so independent-samples $t$-tests should be interpreted with caution. Nonetheless this test revealed that the two parents who were not married ($M = 4.26, SD = .48$) reported higher levels of daily hassles than the 13 parents who were married ($M = 2.44, SD = .84$), $t(13) = -2.93, p = .012$. In addition, unmarried parents reported experiencing significantly greater intensity of daily hassles, $t(13) = -3.28, p = .006$; however, the frequency with which they experienced daily hassles was not significantly different, $t(13) = -2.5, p = .026$.

The relationship between family income and daily hassles was also examined. Families were categorized as having a “low/medium” income if they reported an annual income between $20,000 and $80,000 (n=6), and were categorized as having a “high” income if they reported an
annual income between $80,001 and $200,000 (n=5). Participants were divided into these categories in order to equalize group size. Eleven parents provided their household’s annual income, with five parents indicating they preferred not to answer the question. Overall, household income groups were not significantly different across the daily hassles experienced by the reporting parent, $t(9) = -.04, p = .97$.

The educational level of the parent who completed the daily hassles questionnaire was also examined as a contributing factor to parenting hassles. Parents who indicated they had completed elementary school, high school, community college, or an undergraduate degree were categorized as having obtained an “average” level of education (n=10), whereas parents who had completed a graduate degree or advanced degree (e.g., law degree, medical degree) were categorized as having obtained an “advanced” level of education (n=6). There were no differences between subgroups based on self-reported educational attainment, $t(14) = -1.37, p = .19$.

Finally, independent-samples t-tests were conducted to examine the impact of the employment status of the parent completing the questionnaire. Parents who indicated they had a “full-time paid job” or a “part-time paid job” were categorized as “working” (n=8), whereas parents who indicated they were on “parental leave”, were “unemployed”, were a “stay-at-home” parent, or were a “student” were categorized as “not working” (n=7). There were no differences between subgroups based on self-reported employment status, $t(13) = -1.79, p = .097$.

**Discussion**

**Discussion of Quantitative Results**

The overall purpose of this study was to examine whether parents of kindergarten-age children with ASD experience greater levels of daily hassles than parents of same-age typically
developing children. As hypothesized, the results of this study indicate that parents of children with ASD experience overall higher levels, higher frequency, and higher intensity of daily hassles than parents of typically developing children. These findings align with previous research (e.g., Quintero & McIntyre, 2010) that suggests that parents of children with ASD experience the hassles associated with raising children in the early stages of childhood with more frequency and intensity than parents raising typically developing children.

The second objective was to determine whether the pattern of daily hassles experienced by parents of children with ASD was related to ASD-specific behaviours and challenges. It was hypothesized that daily hassles related to characteristics associated with ASD would be experienced more frequently and intensely by parents of children with ASD. To explore this question, we identified ten items on the PDH questionnaire that correspond to the diagnostic criteria listed in the DSM-5 for Autism Spectrum Disorder and the intensity and frequency of these specific hassles were compared between the parents of children with ASD and the parents of typically developing children. The results indicated that some daily hassles items relating to the diagnostic criteria of restricted, repetitive patterns of behaviour, interest, or activities (e.g., insistence on sameness and inflexible adherence to routine, hyper- or hypo-reactivity to sensory input) were associated with greater intensity and frequency of daily hassles in parents of children with ASD. Specifically, parents of children with ASD reported significantly greater hassles associated with having to deal with their child at the end of the day and having to deal with unexpected changes to their daily routine compared to the typically developing comparison group. These results suggest that the restricted and repetitive patterns of behaviour displayed by children with ASD may contribute more to the increased levels of stress experienced by parents of children with ASD than the challenges related to social-communication deficits; however,
social-communication challenges also played a role in parents’ reported hassles, with trends regarding parents’ difficulties with leaving their child in the morning, and worrying about their child’s happiness while in care.

To further explore this finding, analyses were conducted to compare the responses of parents of children with ASD on a set of daily hassles items ($n=10$ items) related to features of ASD to the remaining daily hassles items not considered to be related to specific features of ASD. Overall, mean scores on the scale compiling daily hassles items related to specific symptoms of ASD was found to be significantly higher than items not related to ASD criteria. This further supports the idea that the higher frequency and intensity of daily hassles that parents of children with ASD are experiencing are related to symptomatic features of ASD, suggesting that there are unique characteristics of children with ASD that contribute to increased levels of parenting stress; however, further exploration of how these characteristics associated with ASD may be impacting parent stress is necessary.

The third objective of the present study was to investigate if there were characteristics of the parent of a child with ASD or the child with ASD that impacted daily hassles. It was hypothesized that features increasing stress in the home (e.g., severe ASD symptomatology, being a single parent, low family income) would be associated with increased frequency and intensity of daily hassles experienced by parents. In order to better understand the factors contributing to increased levels of parenting stress in parents of children with ASD, it seemed important to examine how the adaptive skills of the child with ASD impacted parent-reported stress levels. Parents of children with ASD were asked to describe their child as “verbal” or “non-verbal” and “able to complete self-care” or “unable to complete self-care”. When parent-reported hassles were analyzed as a function of children’s adaptive skills, results indicated that
the child’s verbal ability and self-care skills did not impact reported overall levels of daily hassles, or their frequency or intensity. This suggests that parents of children with ASD experience higher levels of parenting stress regardless of their child’s level of adaptive skills, intimating that the child’s verbal ability and self-care skills are not contributors to increased daily hassles and instead additional factors or characteristics associated with ASD are what influence parent stress levels. Conversely, it is possible that the questions regarding the child’s adaptive skills (i.e., presented as an ‘absent/present’ dichotomy) were not detailed enough to delineate the relationship between parenting stress and the child’s adaptive functioning.

Parental and family demographic factors were also examined to determine their impact on hassles when raising a child with ASD. Within-group comparisons of parents of children with ASD were conducted to examine the impact of their marital status, self-disclosed household income level, employment status, and attained educational level of the parent completing the questionnaire. Results indicated that family income, whether the parent completing the questionnaire had completed a graduate degree or not, and whether the parent completing the questionnaire was in a paid employment position had no impact on the reported daily hassles experienced by that parent. The only demographic factor that was related to changes in reported levels of daily hassles was marital status. Parents who reported being married or common-law experienced lower levels of daily hassles than parents who reported being divorced/separated, or never married. This suggests that the presence of an adult partner in the household plays a role in reducing hassles experienced by parents of children with ASD. In previous research, it has been reported that single parents of typically developing children tend to experience less satisfaction and lower levels of happiness in parenting (Meier, Musick, Flood, & Dunifon, 2016). Although less examined, family-level factors such as intimacy between parents and co-parenting processes
have also been linked to parenting stress (Cooper, McLanahan, Meadows, & Brooks-Gunn, 2009). Further, the dissolution or non-existence of a parenting partnership can lead to changes that can induce stress, such as the loss of economic resources (e.g., being less able to purchase food or child care), associated changes in maternal employment (e.g., having to reenter the workforce, or increase working hours), the loss of social resources (e.g., having to take on a wider range of parenting responsibilities they once shared with their partner or having to move to neighbourhoods with fewer social connections and supports), as well as increases in physical and mental health problems (Cooper et al., 2009). However, because of the very small number of parents who reported being unmarried this result must be interpreted with caution, making it difficult to explore the potential reasons for this difference in experienced daily hassles and parenting stress.

Parent Comments

Additional information regarding the child and family circumstances were brought to the attention of the researcher through other demographic questions and notes left by parents on the questionnaires; however, due to the small size of the clinical sample it was not possible to conduct additional statistical analyses with appropriate statistical power. Thus, some visual and anecdotal analyses were conducted to develop hypotheses and avenues for future research.

On the demographics questionnaire, parents were asked to provide information regarding any additional medical conditions for their child. Visual analysis of these notes suggests a connection between comorbid medical conditions and higher levels of daily hassles in parents of children with ASD. Specifically, parents of children with ASD and a comorbid medical condition appeared to more frequently select higher scores on the PDH questionnaire (indicating more frequent and intense hassles); however, due to the small sample it was not possible to
statistically examine the relationship between comorbid conditions and hassles in parents raising children with ASD. Nevertheless, previous research demonstrates that many individuals with ASD experience comorbid medical and psychiatric conditions, with a high prevalence of gastrointestinal disorders, immune dysregulation, epilepsy, sleep disorders, depression, mood disorder, obsessive compulsive disorder, and aggressive or self-injurious behaviours (Ming et al., 2008). In the current study, four mothers indicated that their child had additional medical concerns, which included epilepsy, anxiety, sleep apnea, Gastroesophageal Reflux Disease (GERD), Nicolaides Baraitser syndrome, asthma, food allergies, Childhood Disintegrative Disorder (CDD), and having to be fed via a G-tube. These four mothers rated between 15 and 36 of the parenting daily hassles questionnaire items as ‘constant’ and ‘big’ hassles. In comparison, mothers who indicated their child did not have any other comorbid conditions rated between 0 and 10 of the parenting daily hassles questionnaire items as “constant” and “big” hassles.

Of the comorbid medical conditions listed by parents, many have been researched within the ASD population. For example, sleep disorders are a common occurrence for children with ASD relative to controls (Celia, Freysteinson, & Frye, 2016), and they are considered to be one of the most common concurrent clinical disorders for children with ASD (Bauman, 2010). Prevalence rates vary widely, ranging from 40-80% of children with ASD showing signs of sleep disorders, compared to 30% of children without ASD (Bauman, 2010). Children with ASD often awaken during the night several times and stay awake for extensive periods of time and these sleep issues affect not only the child, but also the primary caregiver and other household members. Co-occurring sleep problems can exacerbate parental stress and have a negative impact on the caregiver’s quality of sleep and their ability to cope with stress. Gastrointestinal (GI) issues are also commonly found in children with ASD (Celia, Freysteinson, & Frye, 2016),
and many GI disorders have been reported in association with ASD including GERD, gastritis, esophagitis, celiac disease, Crohn’s disease, colitis, inflammatory diseases, food intolerances, and irritable bowel syndrome (Bauman, 2010). The true prevalence of gastrointestinal disorders in those with ASD is unknown, with estimates ranging from 9% to 70% or higher; however, it is not yet known whether GI disorders are more common in the ASD population than in typically developing persons due to widely varying estimates of comorbidity (Bauman, 2010). Research on the impact of gastrointestinal conditions on family stress has shown that families of children with a diagnosis of ASD and other comorbidities such as gastrointestinal symptoms are more likely to report higher levels of stress than parents of children with other developmental disabilities (Valicenti-McDermott et al., 2015).

Seizures are also a common co-occurring medical condition that families of children with ASD must cope with. While the prevalence of a seizure disorder in childhood is approximately 3.2-5.5/1000 (Spindler et al., 2017), ASD and epilepsy co-occur in approximately 30% of individuals diagnosed with either condition (Mannion & Leader, 2014). Generally, families of a child with a seizure disorder have been found to experience significantly more stress, anxiety, and restrictions in family life than other families (Jones & Reilly, 2016), with 45% of parents of a typically developing child with epilepsy reporting high levels of stress (Mannion & Leader, 2014). These high levels of stress are partly explained by the unpredictable nature and risk of seizures (e.g., a seizure can occur suddenly and at any time), which can make parents feel helpless, and the fact that parents must constantly be aware of limitations in everyday activities to avoid accidents in the context of a seizure (Spindler et al., 2017). Parents of children diagnosed with seizure disorders also reported major changes to their daily lives as a result of their child’s diagnosis, including having to leave their job, having to find new living
arrangements, or the dissolution of their marriage. Further, when the child with a seizure disorder is concurrently diagnosed with an intellectual disability, parent strain in all areas of daily life increase (Spindler et al., 2017); however, research has not yet explored the relationship between parental stress, seizures, and ASD.

Additionally, research suggests that asthma and multiple allergies (both food- and environment-related) are common in ASD (Celia, Freysteinson, & Frye, 2016). Medical comorbidities such as allergies are often related to increased irritability and poorer functional outcomes in typically developing children (Lyall, Van de Water, Ashwood, & Hertz-Picciotto, 2015); however, it is still unclear whether immune issues like asthma and allergies similarly impair the level of functioning in children with ASD (Lyall et al., 2015). Due to imbalances in immune and inflammatory processes characteristically associated with ASD, scientists have suggested that ASD and asthma may share common etiologies (Kotey, Ertel, & Whitcomb, 2014). A study examining the co-occurrence of autism and asthma in a sample of children from the National Survey of Children’s Health dataset in the United States found a significantly elevated incidence of asthma in children diagnosed with autism (Kotey, Ertel, & Whitcomb, 2014); however, there was minimal incremental predictive ability of autism status for identification of asthma. Another study found no difference in the prevalence of asthma when comparing children with ASD and typically developing controls (Lyall et al., 2015); however, the prevalence of allergies was slightly higher in children with ASD and in particular, food allergies were reported as more common than in typically developing children (Lyall et al., 2015). This finding that food allergies are more common in children with ASD is anecdotally supported by research noting the frequent gastrointestinal problems and food sensitivities in children with autism (Lyall et al., 2015). Food allergies and asthma in young children are often
accompanied by increased parental anxiety, as fear of an asthma attack or anaphylactic reaction is likely to increase parenting stress. Generally, increased levels of anxiety and stress have been reported in mothers of children with food allergies and asthma (Allen, Bidarkar, VanNunen, & Campbell, 2015; Lau et al., 2014), and researchers have found that caretakers of children with ASD with asthma experience significant strain and are more likely to experience depression (Kotey, Ertel, & Whitcomb, 2014). Overall, research suggests that the presence of comorbid medical conditions in children with ASD is likely to increase parental stress; however, further research is required to explore the complex relationships between ASD, comorbid medical conditions, and parenting stress.

Additional anecdotal information was provided by some parents who chose to leave notes for the researcher on the questionnaires regarding various aspects of the demographic and daily hassles questionnaires. For example, parents provided additional information about their employment situation, their child’s educational placement and other factors impacting their lives (e.g., bussing, child care, child’s level of independence). These anecdotal comments have allowed for some further exploration regarding underlying parental concerns and needs.

Although analyses regarding the impact of employment status were not significant, and indicated that employment status was not a factor in the level of daily hassles experienced by a parent raising a child with ASD, anecdotal comments from three mothers suggested that raising a child with ASD does have an impact on maternal employment. For example, three mothers who completed the questionnaires noted that they were on leave from their jobs; they indicated that they had either left their jobs or had taken leaves of absence in order to care for their child with ASD. While none of the mothers provided further details about the impact of taking time off work, it is plausible to speculate that living in a single-income household while providing full-
time care for a child with a disability is particularly taxing. If it is necessary for one parent to stay at home to provide full-time care for their child, these families end up depending on one income. This can be particularly straining when families are paying for special services such as applied behaviour analysis, behaviour therapy, speech and language, or occupational therapy services. These mothers’ experiences are also supported by other research that has determined that the time required for care of children with ASD in combination with the limited availability and high cost of specialized child care can reduce parents’ abilities to sustain paid employment, which can then lead to losses in income and productivity (Cidav, Marcus, & Mandell, 2012).

Recent research has found that mothers of children with ASD are less likely to work, often work fewer hours per week, and earn substantially less than mothers of children with no special needs (Cidav, Marcus, & Mandell, 2012). In addition, families of children with ASD were more likely to report that a family member reduced or stopped employment because of the child’s needs, and mothers of children with ASD were less likely to be employed than other mothers of children with or without a different “health limitation” (Cidav, Marcus, & Mandell, 2012). Interestingly, there are no reported differences in the employment of fathers of children with ASD, children with another “health limitation”, and children with no “health limitations”, suggesting that mothers are more economically impacted by raising a child with ASD (Cidav, Marcus, & Mandell, 2012). Further, the economic costs of caring for a child with ASD may be higher than those for children with other disabilities. Reasons for this higher cost include limited health insurance coverage for ASD-specific therapies, the prevalence of multiple providers of therapy for ASD-related behaviours thus requiring more transportation time and general involvement from caregivers, and behavioural challenges specific to ASD that can lead to greater disruption in parental work hours and participation (e.g., having to pick up the child in the middle of the
Parents in the current study also provided additional information about their child’s schooling and elaborated on the types of educational services their children received regularly. Four parents noted that their child was receiving Applied Behaviour Analysis (ABA) or Intensive Behavioural Intervention (IBI) services from either private or publicly funded centres; of these four children, three solely received IBI services and one child was simultaneously enrolled in a public kindergarten program. This suggests that even though schools are expected to provide education to all children, they are not able or willing to provide appropriate educational services to children with ASD who have different educational needs. This dearth of appropriate service occurs even though schools have been mandated by the Ontario government to incorporate ABA into programs for students with ASD where appropriate (i.e., Policy/Program Memorandum No. 140). In addition to the three children who were solely enrolled in IBI therapy, two of the children were enrolled in private preschool and kindergarten programs. Both children were an appropriate age for public kindergarten, suggesting the parents preferred having their child enrolled in a private program. These findings may suggest that parents do not feel the traditional public school model is equipped or prepared to properly support and educate their child, leaving them with no other option but to find specialized school programs. Overall, these results suggest the possibility that school boards are not being perceived as fulfilling their obligation to provide appropriate services to children with ASD (e.g., not providing programming that follows the principles of ABA treatment, not training staff in appropriate strategies and techniques for helping children with ASD learn). Research examining parental satisfaction with special education services in general educational systems clearly shows that the needs of children with ASD are not being fully met in public school settings (Lynch &
Irvine, 2009). According to parents, children with ASD are not receiving services that align with the best practices for children with ASD (Dawson & Osterling, 1997), a situation which may contribute to parental dissatisfaction with publicly funded programs. Anecdotally, parents have articulated that they have not felt supported by public school boards. In a study by Tomasi (2015), one mother noted, “I just assumed that the school board would be receptive to working with our team, willing to create the best educational plan available for my son. Boy, was I wrong.” In addition, parents report a major decrease in services when their children start school, which is compounded by a limited number of staff with the training and experience to support students with ASD: “The school system is probably the most regressive and unaccountable system we have left in the province” (Shepherd & Waddell, 2015). Researchers and policymakers have also agreed that the transition to school for children with ASD can be “terrible” and that the school system is “struggling” to accommodate the needs of families of children with ASD (Shepherd & Waddell, 2015). Under the Education Act (1990), the Ministry of Education is responsible for ensuring that all children with exceptionalities in Ontario are able to access appropriate special education programs and services; however, it does not appear that all families feel well-served by the provincial educational system. Further research needs to be conducted to examine the gaps in educational services and to develop programming that meets the academic, social, and developmental needs of children with ASD.

Limitations

There were several limitations in this study, including issues with sample size and selection, participation bias, and the close-ended nature of the questionnaires.

First, in the clinical sample, only parents already affiliated with Holland Bloorview Kids Rehabilitation Hospital and the Autism Research Centre were invited to participate in this
research study (e.g., parents who participated in prior studies, received a psychological evaluation from a clinician, or were connected to the Autism Treatment Network). Due to their connection to Holland Bloorview, these parents may have had more access to resources and supports, which may reduce the levels of hassles experienced by parents.

In addition, parents who returned completed questionnaires elected to participate upon receipt of the invitation email, which may have led to a response bias, in that parents with more time, more resources, or more interest in participating in research may have opted to participate, while parents who had limited time, resources, or interest in research may have chosen not to participate. For example, there may have been a possible overrepresentation of stay-at-home parents/mothers in the ASD sample, as these individuals may have more time available to participate in research studies, whereas parents who work full-time may not be able to prioritize participating in additional research, and therefore may be underrepresented in this study. Moreover, due to the self-selected nature of the sample, parents’ motivation to participate in the study might have been impacted by their own experiences and perceptions of raising a child with ASD. For example, parents who feel particularly overwhelmed by the task of raising a child with ASD might choose to participate in order to express the stress they are feeling, whereas parents who do not feel overwhelmed might feel they do not need to contribute to research on stressors associated with raising a child with ASD.

Furthermore, there was a significant difference between groups in the proportion of parents who had completed some form of post-secondary education (93.8% of the parents of children with ASD versus 20% of the comparison group). One of the reasons for this discrepancy in educational attainment might be due to the fact that recruitment for the ASD group was conducted through Holland Bloorview, and sampled from families who had already participated
in research, whereas the comparison group was recruited from full-day kindergarten programs across the Peel and Dufferin-Peel district school boards. Research on response rates in quantitative family research has indicated that samples are often self-selected, with well-educated and motivated families frequently participating, and lower levels of parental education linked with nonresponding (Rönkä, Sevön, Malinen, & Salonen, 2014). In this study, potential response bias may have led to an overrepresentation of highly educated parents in the ASD group. Future research should aim to sample parents of diverse backgrounds, with special consideration given to ensuring a wide range of representation regarding the educational attainment and employment circumstances of parents.

Another limitation is the difference in the geographic location of the parents of typically developing children and parents of children with ASD. Specifically, all comparison group data was gathered from families residing within the boundaries of the Peel District School Board and the Dufferin Peel Catholic District School Board (encompassing the municipalities of Mississauga, Brampton, Caledon, and Dufferin). In contrast, parents of children with ASD were recruited from across Ontario from municipalities including Toronto, Markham, Brampton, Aurora, Oakville, Windsor, Innisfil, Whitby, Pickering, and Kitchener. Due to the extended geographical range of parents of children with ASD, access to services and the commitment of school boards to serving families of children with ASD likely differed by region. Further, socioeconomic differences, lifestyle, and regional differences may all have contributed to differences in daily hassles between these two groups. In order to fully generalize the results, it would be necessary to expand this study and examine levels of daily hassles in parents of children with ASD and with typically developing children recruited from a variety of rural and urban settings, geographic locations, and service-delivery circumstances (e.g., recruited in
public school systems, from local diagnostic centres) and to gather a large enough sample so that factors such as the impact of such factors could be examined.

Additional analyses for this study are limited because it was not possible to follow-up with families after the submission of their survey responses. Due to the format of the questionnaire and the procedure of implied consent whereby participants’ identities were not linked to their responses, we were not able to follow up with families to gain a more in-depth understanding of the stresses and the impact that raising a child with ASD has on parents and the whole family. It would have been interesting to speak with parents who provided additional anecdotal information on the questionnaires (e.g., explaining that they are on parental leave to care for the child with ASD) to explore the reasons they were unable to find appropriate childcare or public school options, or why they chose to have their child enrolled in IBI programs rather than kindergarten programs.

**Areas for Improvement and Extension**

Going forward, there are several ways to enhance the value of this study. Based on parent replies, it would be informative to ask parents to provide more detailed information about their child’s adaptive skills in order to explore whether variations in adaptive abilities have an impact on parenting stress levels. For example, instead of asking whether the child is verbal or non-verbal and able/not able to complete self-care, specifically asking if their child is able to bathe themselves, dress themselves, and feed themselves, and about the child’s method of communication (e.g., do they speak in words, use augmentative or alternative communication methods) would provide more clarity for parents answering the questionnaire and more detail for researchers in examining what specific adaptive skills are related to higher or lower levels of parenting stress. Further, changes to the questionnaire to include more specific items related to
symptoms of ASD such as sensory issues (e.g., picky eating, fussing about clothing) and sleep difficulties might further illuminate significant differences in the hassles experienced by parents of children with ASD and parents of typically developing children.

Additionally, future research could qualitatively explore what additional services or resources parents would find helpful to reduce the stressors they experience when raising a child with ASD. For example, would having greater access to IBI/ABA intervention services reduce parental stress, or would requiring child care and education providers to have more specialized training in working with children with ASD improve access to and the quality of public services? Hearing directly from parents regarding what they need in order to cope more readily with the stress of raising a child with a disability is critical in order to develop beneficial services and resources.

In our limited age range (57 to 83 months), changes in reported daily hassles were not noted across age for the comparison group; however, there was a positive trend in the relationship between child age and reported levels of hassles in the ASD group. Specifically, within the limited age range of this sample, parents of children with ASD reported higher levels of daily hassles as the age of the child increased, suggesting that parents of children with ASD may experience more hassles as their child grows up. It would be interesting to expand the age range of the study to determine how or whether parent-reported stress changes with the age of the child with ASD. For example, are parents of preschool-age children with ASD experiencing higher levels of daily stressors than parents of adolescents with ASD? Examining how the experience of stress changes over the child’s developmental progression would also provide valuable insight into the types of services and resources families need to manage the stressors associated with child-rearing. Further, examining the frequency and intensity of parenting
hassles in the fathers of children with ASD is important to further our understanding of how childcare responsibilities are split in families where a child has a disability.

Additionally, further research exploring the role of comorbid disorders in the experience of parental stress may provide greater insight into the wide range of reported stress levels of parents of children with ASD. As research begins to substantiate the idea that children with ASD are often diagnosed with comorbid psychiatric and medical conditions, it is important to explore whether these comorbid conditions impact the levels of stress experienced by parents and caregivers and whether it impacts access to services and resources. In the current study, a small number of parents reported that their child had been diagnosed with additional medical or psychiatric/behavioural conditions (e.g., food allergies, asthma, GERD, ADHD); however, due to the limited number of responses, it was not possible to systematically compare the experiences of parents of children with ASD with additional comorbid conditions to the experiences of parents of children diagnosed solely with ASD.

Finally, there are a few changes to the PDH questionnaire and the analytic procedures used to examine the relationship between ASD and parenting daily hassles that would enhance the statistical value of this research. To enhance the validity of the PDH questionnaire utilized in this study, future research should examine the internal consistency of the two parenting hassles scales developed based on DSM-5 criteria for ASD (i.e. Social Communication and Restricted and Repetitive Patterns of Behaviour) to determine if the items selected for each of the scales are accurately representing symptoms of ASD. If internal consistency of these two scales is poor, it would be beneficial to improve the scale by adding or removing items or by developing new items that better reflect deficits in social communication and restricted and repetitive patterns of behaviour. Additionally, comparing how the ASD group and the comparison group rate the
intensity and frequency of the daily hassles identified as related to symptoms of ASD and items not identified as related to symptoms of ASD would allow for greater surety that the items selected as related to symptoms of ASD are in fact specific to the experiences of parents raising children with ASD and are therefore related to characteristics of ASD and not to another shared characteristic of these two groups (e.g., the age range of the children).

Overall, this study provided an initial exploration of the daily hassles associated with parenting a young child with ASD and serves as a starting point for future research exploring the experiences, frustrations, and needs of parents raising these children. Governmental organizations such as the Ministry of Child Services and the Ministry of Education in Ontario should take parental perceptions, reactions, and experiences into account when developing, planning, and providing services to special populations. For example, one to two years of early and intensive behavioural intervention (EIBI) has been shown to reduce stress for mothers (Eikeseth et al., 2015). Combating parental stress and fostering parental well-being are critical for positive family functioning and child development and should be a priority of the government to assist our most vulnerable populations, such as the parents of children with ASD.
References


of Autism and Developmental Disorders, 22(2), 205-216.


Table 1
*Frequency and Intensity of Daily Hassles Reported by Mothers of Children with and without ASD*

<table>
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<tr>
<th></th>
<th>ASD</th>
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<th>t</th>
<th>P</th>
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<td>n</td>
<td>M</td>
<td>SD</td>
<td>n</td>
<td>M</td>
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<td>2.88</td>
<td>1.02</td>
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<td>1.98</td>
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**Table 2**

*Differences in Specific Hassles Reported by Mothers of Children with and without ASD*

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<th>Comparison</th>
<th>M</th>
<th>SD</th>
<th>M</th>
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<td></td>
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<tr>
<td>To leave my child in the morning because he/she gets upset</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>2.50</td>
<td>1.02</td>
<td>1.81</td>
<td>1.22</td>
<td>1.31</td>
<td>.022</td>
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<td></td>
</tr>
<tr>
<td>Intensity</td>
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<td>.96</td>
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<tr>
<td>To get my child to tell me about his/her day</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
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<td>1.77</td>
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<td>To find the time to play with my child</td>
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<td></td>
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<td></td>
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<td></td>
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<td></td>
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<tr>
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<td><strong>Restricted/Repetitive Behaviour Hassles</strong></td>
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<tr>
<td>To get my child ready in the morning</td>
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<td></td>
<td></td>
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<td></td>
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<td>1.79</td>
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<td>To deal with my child when he/she is exhausted at the end of the day</td>
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<td>To deal with unexpected changes to our routine</td>
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<td>To know what my child should be able to do at his/her age</td>
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<td>.022</td>
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<td>To know whether my child’s behaviour is a problem or whether he/she is behaving like other kids his/her age</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>1.03</td>
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<td></td>
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<tr>
<td>Intensity</td>
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APPENDIX A

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: A Comparison of Parenting Daily Hassles in Parents of Children with Autism and Typically Developing Children

Principal Investigator: Dr. Jessica Brian, PhD, C.Psych, co-lead of the Autism Research Centre at Holland Bloorview Kids Rehabilitation Hospital. Email: jbrain@hollandbloorview.ca, Phone: 416-425-6220 ext. 3716

Student Researcher: Katherine Stover, M.A. Student, School and Clinical Child Psychology Program, OISE, Email: kstover@hollandbloorview.ca, Phone: 416-425-6220 ext. 3716

Dear Parent/Guardian,

My name is Katherine Stover. I am a Master’s student in the Autism Research Centre at Holland Bloorview, working under the supervision of Dr. Jessica Brian. I am conducting a research study to better understand the stressors faced by parents of children with autism. I would like to invite you to participate in this research study. Before agreeing to take part in this study, it is important that you understand how you will be involved. This consent form provides you with information to help you make an informed choice.

What is the study about?

You are being asked to consider participating in this study because you are a parent of a child with autism, and you have previously indicated interest in participating in research being done at the Autism Research Centre at Holland Bloorview. The goal of this study is to determine whether parents of children with autism spectrum disorders (ASD) experience greater levels of daily hassles (e.g., smaller, daily stressors that parents have to deal with, such as finding child care for sick children, making lunches, etc) than parents of children without ASD. In addition, we hope to determine which areas of daily living are more difficult for parents of children with ASD in order to recommend services, interventions, and programs that will help parents reduce stress. The purpose of this study is to determine if parents of children with ASD have higher levels of daily hassles than parents of typically developing children, and to determine which areas of daily responsibilities cause more stress for parents of children with ASD. We will be comparing answers on the questionnaires you complete as part of this study to the same questionnaires which were filled out by parents of children who do not have autism. This comparison group information comes from a study on full-day kindergarten in Ontario led by Dr. Janette Pelletier at the University of Toronto.

We expect about 100 parents will participate in this study. We want to invite you to participate.

How will I be involved in this study?

If you decide to participate in this study you will be asked to do the following:

1) Complete the Demographics Questionnaire, which asks questions about your child with autism regarding their age of diagnosis, symptoms of autism, other medical conditions, date of birth, gender, and school enrollment, as well as questions related to parental education and employment. This questionnaire should take no more than 10 minutes to complete.

2) Complete the Parenting Daily Hassles Questionnaire, which asks you to rate the intensity (how much of a hassle something is) and the frequency (how often something is a hassle) of 42 different items relating to stressors that parents of young children experience. This questionnaire should take no more than 20 minutes to complete.

3) Return the completed questionnaires in the pre-addressed envelope to the researcher. Keep the consent form for your own records. By returning your completed questionnaire, you have agreed to participate in the study.

Will anyone know what I say?

We will respect your privacy. No information about who you are will be given to anyone or be published without your permission, unless the law makes us do this. For example, the law could make us give information about you:

- If you/your child have been abused (physically, verbally, sexually, or emotionally)
- If you have an illness that could spread to others
- If you talk about suicide (killing yourself), or
• If the court orders us to give them the study papers

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published. All the information we collect about you and your family will be kept confidential. This means that all of the information about you is private and people outside of the research team will not know this information. Data gathered in this study may be used by the research student, Katherine Stover, in her PhD dissertation.

People from the Holland Bloorview Research Ethics Board may look at the study records to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines.

Do I have to do this?
You do not need to do this study. It’s okay if you decide not to take part. If you decide to take part but then wish to change your mind, you will be unable to remove your questionnaire from the data set because it was submitted anonymously.

Your decision whether to participate in this study or not will not affect the services you and your child get from Holland Bloorview.

What are the risks and benefits?
There are no known risks to you from participating in this study. Participation in this study will not involve any additional costs to you and you will not be paid to participate in this study.
You may not benefit directly from participating in this study. However, your participation may benefit the community more broadly by increasing our understanding of the stressors faced by parents of children with ASD, and provide research evidence for the need for different types of supports for families coping with autism.
If as a result of filling out the questionnaires for this study you feel overwhelmed or in need of support, please consider contacting your local chapter of Autism Ontario.

You have the right to be informed of the results of this study once the entire study is complete. Once completed, the results of this study will be available on the Autism Research Centre website (http://research.hollandbloorview.ca/researchcentreslabs/autismresearchcentre/studies).

Do the investigators have any conflicts of interest.
I (PI) and the other research team members have no conflicts of interest declare related to this study. This project has no specific funding attached to it. Katherine Stover is funded by a SSHRC CGS-M student award.

What if I have questions?
Please call Katherine Stover to explain anything you don’t understand before signing the consent form. Her phone number is 416-425-6220 extension 3716. If you leave a message, she will return your call within 48 hours.
Alternatively, you may email Katherine Stover to arrange a time to speak on the phone at kstover@hollandbloorview.ca.
If you have any questions about your rights as a research participant, please contact the Holland Bloorview Research Ethics Board at 416-425-6220 ext. 3507.

The research study you are participating in may be reviewed for quality assurance to make sure that the required laws and guidelines are followed. If chosen, (a) representative(s) of the Human Research Ethics Program (HREP) may access study-related data and/or consent materials as part of the review. All information accessed by the HREP will be upheld to the same level of confidentiality that has been stated by the research team.
INFORMED CONSENT FORM
HOLLAND BLOORVIEW KIDS REHABILITATION HOSPITAL

Re: A Comparison of Daily Parenting Hassles in Parents of Children with Autism and Typically Developing Children

Please complete this form and keep it for your own records.

By signing this form, I confirm that:
- Katherine Stover explained this study to me and answered all of my questions.
- I read the attached Informed Consent Form dated _________ and understand what this study is about.
- I understand the known risks and benefits of participating in this research study.
- I understand that I do not have to participate in this study. My decision about taking part in the study will not affect the services my child and I get at Holland Bloorview.
- I am free now, or in the future to ask questions about the study.
- I know that study records related to myself and my child will be kept confidential.
- I agree to participate in this study.

______________________________  ______________________  _________
Parent’s Name (please print)   Signature            Date

I have explained this study to the above participant/parent and have answered all their questions.

______________________________  ______________________  _________
Name of Person Obtaining Consent  Signature            Date
APPENDIX B
Demographic Questionnaire

A. Child Information

Date of Birth: ___ / ___ YYYYY / MM

Sex: □ M □ F

Does this child have a diagnosis of ASD? □ YES □ NO
(i.e., autism, Asperger’s syndrome, PDD-NOS, autism spectrum disorder)

If YES, please specify: __________________________ Age when first diagnosed? __________

Who made this diagnosis? __________________________ Other medical conditions? ______________

Please check the boxes that describe your child’s symptoms:

□ Verbal
□ Non-verbal
□ Able to complete self-care (e.g., toileting, dressing, feeding)
□ Unable to complete self-care (e.g., toileting, dressing, feeding)

Is your child currently attending one of the following?

□ Preschool: Start Date - __________
□ Kindergarten – Half Day: Start Date - __________
□ Kindergarten – Full Day: Start Date - __________
□ Other – please specify: __________________________

Is the school/center your child attends

□ Private (e.g., Montessori, private home care, private religious school, private school)
□ Public (e.g., public school, public Catholic school, public French school)

B. Parent/Guardian Information

PARENT/GUARDIAN A (PRIMARY CAREGIVER): RELATIONSHIP TO CHILD: __________

Highest level of education completed:

□ Less than seventh grade □ Junior high school (8th or 9th grade) □ Partial high school (10th or 11th grade) □ High school graduate
□ College or specialized training □ Partial University □ University undergraduate (e.g., B.A.) □ Graduate training (e.g., M.A., Ph.D., M.D.)

Current occupation (when not on parental leave): ________________________________
Current employment status:

☐ Full-time paid job (at least 35 hours a week)  ☐ Part-time paid job (less than 35 hours a week)
☐ Full-time student (3 or more classes a semester)  ☐ Part-time student (1 or 2 classes a semester)
☐ Not currently working  ☐ Other, please specify: _________________________

PARENT/GUARDIAN B: RELATIONSHIP TO CHILD: _________________________

Highest level of education completed:

☐ Less than seventh grade  ☐ Junior high school (8th or 9th grade)
☐ Partial high school (10th or 11th grade)  ☐ High school graduate
☐ College or specialized training  ☐ Partial University undergraduate (e.g., B.A.)
☐ University undergraduate (e.g., M.A., Ph.D., M.D.)  ☐ Graduate training

Current occupation (when not on parental leave): ____________________________

Current employment status:

☐ Full-time paid job (at least 35 hours a week)  ☐ Part-time paid job (less than 35 hours a week)
☐ Full-time student (3 or more classes a semester)  ☐ Part-time student (1 or 2 classes a semester)
☐ Not currently working  ☐ Other, please specify: _________________________

PARENTS'/GUARDIANS' MARITAL STATUS:
Check in reference to the current relationship between Parent/Guardian A and Parent/Guardian B

☐ Married  ☐ Common Law  ☐ Separated  ☐ Divorced  ☐ Never married or lived together  ☐ Widowed

HOUSEHOLD INCOME: Total household income last year before taxes (refer to child’s primary household).

☐ $20,000 or less  ☐ $80,001 - $100,000  ☐ $200,001 or higher
☐ $20,001 - $40,000  ☐ $100,001 - $125,000  ☐ I don’t know
☐ $40,001 - $60,000  ☐ $125,001 - $150,000  ☐ I prefer not to answer
☐ $60,001 - $80,000  ☐ $150,001 - $200,000

What is the relationship of the parent who completed this questionnaire to the child with ASD?

___________________________________________________________________________
# APPENDIX C
## Early Childhood-Parenting Daily Hassles (EC-PDH)

### Instructions:
- The statements below describe events or experiences that routinely affect families with young children. These events/experiences sometimes make life difficult.
- For each item please circle: (1) **how often it affects you** (Never, Rarely, Sometimes, A lot, or Constantly) **AND** (2) **how much of a hassle it has been for you** for the **past month**.
- If the item does not apply to you, please circle N/A. For example, if English is your only language, then circle N/A for the question asking about difficulties communicating with the school in English.

<table>
<thead>
<tr>
<th>Please be sure to fill in both columns!</th>
<th>How often it affects you</th>
<th>How much of a hassle it is for you</th>
<th>Item does not apply</th>
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</thead>
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<td></td>
<td></td>
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<td>Get my child ready in the morning</td>
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<td>1 2 3 4 5</td>
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<tr>
<td>Find the time to make my child’s lunch and snacks</td>
<td>1 2 3 4 5</td>
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<td>N/A</td>
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<td>Transport my child to school or child care in the morning</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
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<tr>
<td>Leave my child in the morning because he/she gets upset</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Interrupt my day or make special arrangements to get my child from school to child care (or from child care to school)</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
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<tr>
<td>Worry about my child’s safety as he/she is taken back and forth between child care and the school</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Be separated from my child for long periods of time during the day</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Focus on what I need to do during the day because I worry about how my child is doing</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Rush at the end of the day to pick up my child</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Deal with my child when he/she is exhausted at the end of the day</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Get my child to tell me about his/her day</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Have to keep track of my child’s daily schedule</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Have to deal with unexpected changes to our daily routine</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Have to make alternate arrangements for my child when he/she is sick</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know what to do about school and child care when my child tells me he/she is not feeling 100%</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find the time to read with my child</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find the time to play with my child.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know what my child should be able to do at his/her age</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know whether my child’s behaviour is a problem or whether he/she is behaving like other kids his/her age</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Please be sure to fill in both columns!

<table>
<thead>
<tr>
<th>Item</th>
<th>How often it affects you</th>
<th>How much of a hassle it is for you</th>
<th>Item does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get good advice on how to handle my child’s challenging behaviours</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Get good advice on how to support my child’s learning at home</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find parenting programs that meet my needs</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know what programs or services are available in my community</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Feel like an outsider among the parents of my child’s classmates</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find the opportunity to talk with other parents with young children</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Stay in contact with the child care staff about day-to-day things</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know whether my child is happy while he/she is in child care</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find the opportunity to discuss issues of concern with the child care staff</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Be satisfied with the child care program because I worry about the quality of my child’s experience</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Avoid spending money on certain things because I have to pay for child care</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Stay in contact with the classroom teacher about day-to-day things</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know whether my child is happy while he/she is at school</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find the opportunity to discuss issues of concern with the classroom teacher</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know what my child is learning at school</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Know whether my child is learning enough at school</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Agree on what’s best for my child because the school doesn’t know my child the way I do</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Be satisfied with the school program because I worry about the quality of my child’s experience</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Communicate with the school because English is not our family’s first language</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find out about my child’s day because multiple people care for my child throughout the day</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Find the time to participate in my child’s classroom activities</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Understand how things work at my child’s school</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
<tr>
<td>Understand what the school expects from me as a parent</td>
<td>Never 2 3 4 5</td>
<td>No Hassle 2 3 4 5</td>
<td>N/A</td>
</tr>
</tbody>
</table>
**APPENDIX D**

**Parenting Daily Hassles**

**Telephone Recruitment Script**

“Hello. May I please speak with ____________________?

My name is Katherine Stover. I am a master’s student from the Autism Research Centre at Holland Bloorview. When you registered in POND/received services from the Autism Research Centre, you agreed to be contacted about research projects being done in ARC, and I am calling about a new study being done. Are you interested in hearing about this project?

**If NO,** That’s fine. I will not contact you again. Thank you for your time.

**If yes,** Great!

Is now a good time to talk for a few minutes?

**If no,** Would there be a better time for me to call?

**If still no,** That’s fine. I will not contact you again. Thank you for your time.

Your son’s/daughter’s name is ___________________ (child’s name). Are you the primary caregiver for your child? Is your child between the ages of 3 years and 11 months and 6 years and 6 months? Have they attended 4 or more months of kindergarten?

Let me tell you more about this study. Please interrupt me at any time if you have a question. For this study, we are asking parents to fill out a questionnaire about the daily stresses they face in raising young children with autism. This questionnaire will help us understand the daily hassles that are specific or more difficult to deal with for parents of children with autism than for parents of typically developing children.

Are you still interested in participating?

**If NO,** That’s fine. Thank you for your time.

**If YES,** Great!

You will receive a letter in the mail that explains this study further, along with the parent hassles questionnaire, and a demographics questionnaire. Please read the letter, and if you agree, complete the surveys and return it to me using the envelope that we provide. You keep the information letter and consent form I have sent you. If you have any questions after reading the letter, instructions on how to contact me are in there.

Could I please confirm your mailing address? **Read the mailing address that is on file and make corrections where necessary.** Do you have any questions?

If you think of any other questions or would like to speak to me about this at anytime, please call me at 416-425-6220 extension 3716.

Thank you.
APPENDIX E

Parenting Daily Hassles
Regular Mail and Email Recruitment Letter

Dear ________,

My name is Katherine Stover. I am a Master’s student from the Autism Research Centre at Holland Bloorview. When you received services from ARC, you agreed to be contacted about research projects being done in ARC, and I am emailing about a new study being done.

For this study, we are asking parents to fill out a questionnaire about the daily stresses they face in raising young children with autism. This questionnaire will help us understand the daily hassles that are specific or more difficult to deal with for parents of children with autism than for parents of typically developing children.

If you are interested in participating in this research project, please email me or call me to confirm your interest and confirm your mailing address.

If you agree to participate, you will receive a letter in the mail that explains this study further, along with the parent hassles questionnaire, and a demographics questionnaire. Please read the letter, and if you agree, complete the surveys and return it to me using the envelope that we provide. If you have any questions after reading the letter, instructions on how to contact me are in there.

If you have any questions or would like to speak to me about this at anytime, please email (kstover@hollandbloorview.ca) or call me at 416-425-6220 extension 3716.

Thank you,

Katherine Stover
M.A. Student
School and Clinical Child Psychology, OISE, University of Toronto
Autism Research Centre, Holland Bloorview Kids Rehabilitation Hospital

Participate in Research at Holland Bloorview