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Factors That Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder

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FACTORS THAT INFLUENCE PARENTS TOWARD EARLY DIAGNOSIS OF
AUTISM SPECTRUM DISORDER

By

Debra D. Barrie

A Thesis
Submitted to the Faculty of Graduate Studies
through the Department of Psychology
in Partial Fulfillment of the Requirements for
the Degree of Master of Arts at the
University of Windsor

Windsor, Ontario, Canada

2010

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Factors that Influence Parents toward Early Diagnosis of Autism Spectrum Disorder

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Declaration of Originality

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Abstract

This study examined factors influencing parents toward obtaining early diagnoses of Autism Spectrum Disorder (ASD) for their children. Parents of children diagnosed with ASD at or before 30 months became concerned about development at an average of 16 months, while parents of children diagnosed later became concerned at 25 months. The younger children were at initial concern, the younger they received their diagnoses. Over 58% were referred for assessment of ASD by speech and language pathologists or occupational therapists. Parents reported that their persistence was a major factor in obtaining diagnoses. Parents described feelings of relief and gratitude when they received the diagnosis because they had direction on how to help their children. Parents emphasized their need to be heard when they approached health professionals about their concerns for their children's development. Implications of the results for promoting public awareness of early symptoms related to ASD are discussed.

Dedication

I would like to dedicate this research to all of the families and children living with Autism Spectrum Disorder that I have had the privilege to know and call friends. You will always hold a special place in my heart; this research is for you.

I would also like to dedicate this research to my grandson, Ross Alexander. You continue to me bring me unending joy and I have great dreams for your future!

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Chapter I

Introduction

Overview

Autism Spectrum Disorder (ASD) are a group of developmental disabilities characterized by repetitive, stereotyped behaviours and pervasive impairments in socialization and communication (American Psychiatric Association [APA], 2000; Johnson, Myers, & the Council on Children with Disabilities, 2007) and are recognized as the most common of the neurological disorders affecting children today (Bryson, Zwaigenbaum, & Roberts, 2004; Newschaffer et al, 2007). Recent prevalence studies have estimated ASD to affect on average 1 in 100 children in the United States, with the majority of parents developing concerns before their children are three years old (Kogan et al., 2009; The Centres for Disease Control and Prevention (CDC), 2009). Although there is little data on the prevalence of ASD in Canada, the few existing studies suggest prevalence in Canada has been similar to that reported of the United States (Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006; Ouellette-Kuntz et al., 2006).

Early signs of ASD are apparent in very young children (Baranek, 1999; Bryson et al., 2007; Osterling & Dawson, 1994; Shumway & Wetherby, 2009; Werner, Dawson, Osterling, & Dinno, 2000; Watt, Wetherby, Barber, & Morgan, 2008; Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005) making it feasible to reliably diagnose ASD by 24 months of age (Lord, 1995; Matson, Wilkins, & González, 2008; Oosterling et al., 2010; Stone et al., 1999; Turner, Stone, Pozdol, & Coonrod, 2006; van Daalen et al, 2009; Zwaigenbaum et al., 2009). There is mounting evidence of the importance of early identification of ASD and early intervention. (Harris & Handleman,

2000; Horner, Carr, Strain, Todd, & Reed, 2002; Mansell & Morris, 2004; Moore & Goodson, 2003; Turner et al., 2006). Despite this evidence, early diagnosis of ASD is rare (Baron-Cohen et al., 1996; Mandell, Novak, & Zubritsky, 2005).

Parents of children diagnosed with ASD often have concerns about their children's development long before their children receive a formal diagnosis (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997). Their concerns often begin during the first two years of their children's life and include concerns about: 1) language development (e.g., little babbling by 12 months of age), 2) atypical social development (e.g., reduced shared attention, weak eye-to-eye gaze), and 3) challenging behaviours (e.g., tantrums, crying, sleep issues) (Chawarska, Klin, Hannigen, Dichtel, & Volkmar, 2007; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Young, Brewer, & Pattison, 2003). Many parents first seek answers for their concerns from their family physician (Howlin & Moore, 1997; Osborne & Reed, 2008). They are often told there is "no need to worry" or that their children "will grow out of it" (Howlin & Moore, 1997; Maurice, Mannion, Letso, & Perry, 2001). Frequently, parents experience long wait lists because of referrals to a variety of professionals before they finally obtain a diagnosis of ASD for their children (Mandell et al., 2005). Consequently, many children are not diagnosed with ASD until 4-6 years of age (Howlin & Moore, 1997; Shattuck et al., 2009; Siklos & Kerns, 2007), missing the benefits of early intensive intervention.

Some parents, however, do manage to obtain diagnoses of ASD for their children at or before 30 months and research has demonstrated these children have a more positive outcome when compared to children diagnosed at a later age (Turner et al., 2006).

The present research investigated parents' experiences as they navigated the diagnostic process to obtain early diagnoses of ASD for their children. Investigations were conducted to examine initial concerns parents had about their children's development, the decisions parents made, and the barriers they perceived while seeking professional help. The overriding goal of the present research was to identify factors that influenced parental experiences as they moved toward achieving an early diagnosis for their children. The Health Beliefs Model (HBM; Rosenstock, 1990) was used as a theoretical framework for understanding these factors. The HBM posits that parents will take action if they believe: a) there is a potential threat to their children (e.g., ASD), b) the threat is severe, c) the benefits of taking action outweigh the barriers, and d) their level of self-efficacy (i.e., their ability to achieve the action) is high (see Figure 1) (Rosenstock, 1990).

Clarification of Definitions. The term Autism Spectrum Disorders (ASD) was used throughout this paper to refer to the terms Autism, Autistic Disorder, Asperger's Disorder, PDD-NOS, Atypical Autism, and Other Pervasive Developmental Disorders unless it was necessary to designate a specific subtype defined under the broader umbrella of Pervasive Developmental Disorders (PDD) referred to in the Diagnostic and Statistical Manual – 4th Edition, Text Revision (DSM-IV-TR). Similar to the DSM-IV-TR, The International Classification of Diseases (ICD-10) published by the World Health Organization (WHO) also includes the category Pervasive Developmental Disorders. Although the ICD-10 is comprised of more types of disorders than the DSM-IV-TR, both groupings of sub-types are comparable (Nachshen et al., 2008). Similar to the DSM-IV-TR, the ICD-10 includes the sub-types Childhood Autism and Asperger's Syndrome. The

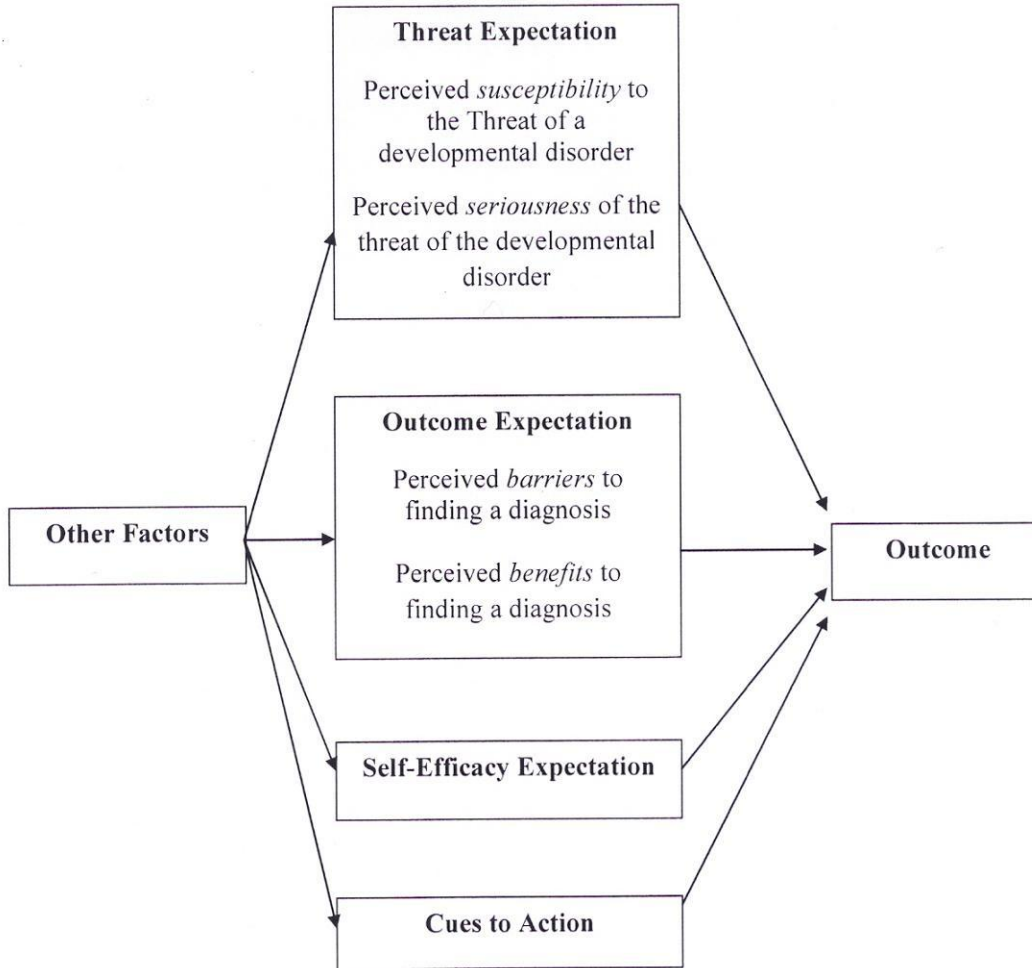


Figure 1. Health belief model; Rosenstock, 1990.

DSM-IV-TR subtype PDD-NOS is analogous to both the sub-types Other Pervasive Developmental Disorders and Atypical Autism in the ICD-10 (Nachshen et al., 2008).

Early diagnosis of ASD was defined as a diagnosis given to a child when the child was 30 months of age or younger and obtained through the assessment of a paediatrician, family physician, clinical psychologist, or a child psychiatrist.

Empirical Review

A systematic review of the literature was undertaken utilizing the PsycINFO and PubMed databases with a combination of the following criteria: (“autistic” or “autism” or pervasive developmental disorder” or “ASD”); (“prevalence”) and (“Canada” or “US” or “United States”); (“parental concerns” or “early concerns” or “developmental concerns”); (“early identification” or “early diagnosis” or “diagnosis” or “early detection”); (“outcome” or “optimal outcome” or “recovery” intervention”) (“language” or “joint attention” or communication”); (“diagnostic stability” or “stability of diagnoses”); (“prospective study” or “retrospective study” or “home videos”).

Clinical Features

Autism Spectrum Disorders (ASD) are a set of complex neurodevelopmental disorders that include the sub-types Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) (Bryson et al., 2004). Clinicians determine the presence of ASD by the observation of a set of behavioural impairments: (1) social interaction, (2) communication, and (3) rigid and/or repetitive behaviour (Bryson et al., 2004; Matson et al., 2008; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). The Diagnostic and Statistical Manual – 4th Edition, Text

Revision (DSM-IV-TR) and the International Classification of Diseases (ICD-10) describe the standard criteria for diagnosing ASD.

Impairment in social interaction. Children with ASD have difficulty with non-verbal social behaviours. During interactions with other people, children with ASD are less likely to make eye-to-eye contact or smile socially compared to typically developing children (Filipek, et al., 1999; Werner & Dawson, 2010; Wetherby, Watt, Morgan, & Shumway, 2007; Zwaigenbaum et al, 2009). Children with ASD may also display lower interest in interacting with their parents or in making friends with other children (Filipek, et al, 1999; Folstein, 1999). Although this may diminish as the children grow older, their attempts to make friends continue to appear awkward and socially inept (Folstein, 1999). Children with ASD are also less likely to seek shared enjoyment with other people (APA, 2000; Werner & Dawson, 2010; Wetherby, Watt, Morgan, & Shumway, 2007; Zwaigenbaum et al, 2009). For example, when they become aware of something exciting in their environment, such as a puppy or special toy, they may not attempt to get the attention of a parent or other individual to share their enjoyment (APA, 2000). Some children may only attempt to get the attention of a parent to fulfill a specific need, such as getting a desired toy or a drink of juice (Folstein, 1999). In addition, children with ASD may appear to have little or no awareness of another person's needs or emotional distress (APA, 2000; Hobson, Harris, García-Pérez, & Hobson, 2009). They may not notice or appear to care if someone near them is crying or they may not respond if someone nearby falls and is hurt.

Impairment in communication. Impairment in both verbal and non-verbal communication is evident in children with ASD (APA, 2000). Spoken language is often

delayed or may not develop beyond a few words and is not compensated for by other non-verbal attempts to communicate, such as gesturing or eye contact (APA, 2000; Folstein, 1999; Zwaigenbaum et al, 2009). Those children that do develop adequate spoken language may have difficulty initiating or sustaining conversation with others (APA, 2000). Verbal children with ASD tend to use speech to make requests or relate information, but rarely to socialize or exchange information (Folstein, 1999). The quality of speech is often monotone, with little variation in intonation (Folstein, 1999; Zwaigenbaum et al, 2009). Echolalia, repeating words another person has said, is a typical feature of speech in children with ASD (Folstein, 1999; Zwaigenbaum et al, 2009). They may also use echoed language to request a desired item. For example, the child might say, “do you want some juice?” every time they want a glass of juice (Folstein, 1999). Children with ASD often demonstrate less social imitative or make-believe play than do other children at a similar developmental level (APA, 2000; Zwaigenbaum et al, 2009). For example, children with ASD may use toys in atypical ways, such as lining them up or continuously spinning the wheels, instead of pretending to race the cars against each other or drive the car to the gas station.

Restricted repetitive and stereotyped patterns of behaviour. Children with ASD often become intensely preoccupied, or overly focused on certain interests or activities (Folstein, 1999; Richler, Huerta, Bishop, & Lord, 2010; Watt, Wetherby, Barber, & Morgan, 2008; Zwaigenbaum et al, 2009). Children with ASD are often inflexible with routines or rituals (APA, 2000; Folstein, 1999; Richler, Huerta, Bishop, & Lord, 2010; Watt, Wetherby, Barber, & Morgan, 2008). For example, they may insist on always taking the same route to the grocery store or repeating a specific ritual every time

they leave the house, becoming very upset if their routines are disrupted (APA, 2000). Children with ASD may also demonstrate stereotyped, repetitive motor actions, such as hand flapping or finger flicking (APA, 2000; Richler, Huerta, Bishop, & Lord, 2010; Watt, Wetherby, Barber, & Morgan, 2008). They may also have an intense preoccupation with certain parts of objects, such as buttons or certain movement, such as the spinning of the wheels on a toy car (APA, 2000; Richler, Huerta, Bishop, & Lord, 2010; Watt, Wetherby, Barber, & Morgan, 2008).

DSM-IV-TR diagnostic criteria. DSM-IV-TR (2000) diagnostic criteria for Autistic Disorder include a minimum of two impairments in social interaction, at least one deficit in communication, and at least one restricted, stereotyped behaviour. Onset of the impairments must be evident before the age of three (APA, 2000). To meet criteria for Asperger's disorder, impairments in social interaction and restricted, stereotyped behaviours must be present, with relatively intact communication and cognitive skills (APA, 2000). However, children are not diagnosed with Asperger's Disorder if they meet the criteria for Autistic Disorder (APA, 2000). Children may be diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) if their symptoms occur after the age of three, or are at a sub-threshold level (APA, 2000).

Feasibility of Early Diagnosis of ASD

There is much evidence to support the feasibility of identifying children with ASD by the time they are 18 to 36 months of age (Kleinman et al, 2008; Nachshen, et al., 2008; Pandey et al., 2008; Saint-Georges et al, 2010; Turner, et al., 2006). Retrospective studies examining early home videotapes of children with ASD have revealed early signs and symptoms by the first year of life (e.g., Baranek, 1999; Maestro et al., 2005; Osterling & Dawson, 1994; Werner et al., 2000). Recent prospective, longitudinal studies

following high-risk siblings of children with ASD have identified early behavioural profiles and developmental trajectories to aid in early identification of ASD (e.g., Brian et al., 2008; Bryson et al., 2007; Landa, Holman, & Garrett-Mayer, 2007; Loh et al., 2007; Ozonoff et al., 2008; Watt et al., 2008; Zwaigenbaum et al., 2005). Finally, the combination of clinical judgement with standardized diagnostic tools has made it possible to diagnose children with ASD reliably between 18 and 24 months as evidenced by reliability and stability studies (Brian et al., 2008; Lord, 1995; Matson et al., 2008; Pandey et al., 2008; Stone et al., 1999; Wetherby, Brosnan-Maddox, Peace, & Newton, 2008, Zwaigenbaum, 2010).

Retrospective studies. Retrospective studies of family home videotapes have helped to identify early signs of ASD. Osterling and Dawson (1994) found that differences between infants with ASD and typically developing infants are evident at 12 months of age. Using retrospective home videos of children's first birthday parties, they compared early behaviour of 11 infants later diagnosed with ASD to that of 11 typically developing infants. The children with ASD showed significantly less social behaviour and joint attention and significantly more autistic symptoms (failing to orient to name, self-stimulation, covering their ears) compared to the children with typical development (Osterling & Dawson, 1994).

Werner, Dawson, Osterling, and Dinno (2000) examined home videotapes taken at 8 to 10 months of age to see if impairments in social attention and affective responsiveness would be evident before one year of age. Using the same sample of children as Osterling and Dawson (1994) and including eight additional children (four with autism and four typically developing children), significant group differences were

found in the social attention domain (Werner et al., 2000). Infants later diagnosed with ASD oriented to the calling of their name 37% of the time compared to 75% of the time for typically developing infants. In addition, infants later diagnosed with ASD were less likely to look at a face while smiling compared to typically developing infants (Werner et al., 2000).

Using a behavioural summarized evaluation scale, Maestro et al. (2005) examined 40 home videos taken during the first year of life of children later diagnosed with ASD. The majority of the children (87.5%) showed patterns of social withdrawal, poor social initiative, hypoactivity, and difficulty with emotional modulation.

Prospective studies. Although retrospective studies have added to the knowledge base of early signs of ASD, prospective, longitudinal studies of infants at high-risk for ASD allow researchers the opportunity to observe early manifestations of ASD as they develop (Zwaigenbaum et al., 2005). Zwaigenbaum et al. (2005) followed 150 high-risk infants, all of whom had an older sibling with ASD, and 75 low-risk infants from the age of 6 months. Inclusion criteria for the low-risk infants included full term gestation, birth weight greater than 2500 g, and no first or second-degree relatives with ASD (Zwaigenbaum et al., 2005). The researchers aimed to provide a picture of the behavioural profiles and developmental trajectories in the very early course of ASD. After following 65 of the high-risk infants and 23 of the low-risk infants to 24 months of age, preliminary results indicated that infants later diagnosed with ASD could be distinguished from typically developing infants and from other infant siblings as early as 12 months of age (Zwaigenbaum et al, 2005). Early indicators of ASD at 12 months included behavioural markers such as poor eye-to eye contact, abnormalities in visual

tracking, a marked difficulty in shifting visual attention from one stimulus to another, and failure to orient to their name (Zwaigenbaum et al., 2005). Patterns of temperament included more frequent and intense distress reactions than typically developing infants, a tendency to fixate on a specific object in the environment, and reduced social smiling, social interest, and expression of positive affect (Zwaigenbaum et al., 2005). Evidence of early language delays in expressive and receptive language was also noted, with infants later diagnosed with ASD having fewer gestures and fewer understood phrases than typically developing infants (Zwaigenbaum et al., 2005).

Landa, Holman, and Garrett-Mayer (2007) examined patterns of social and communication development of 107 infants at high risk for ASD and 18 infants at low risk from the age of 14 to 36 months. Sixteen of the high risk infants were given a diagnosis of ASD at 14 months of age (early-diagnosis group) and an additional 14 high risk infants were diagnosed with ASD at 36 months (later-diagnosis group) (Landa, Holman, & Garrett-Mayer, 2007). The early-diagnosis group exhibited atypical development in joint attention, initiation of communication with others, and in vocal and non-vocal forms of communication (Landa et al., 2007). They were also less likely to combine play with social interaction (Landa et al., 2007). Children in the later-diagnosis group exhibited signs of ASD by their second birthday (Landa et al., 2007). By 24 months, both the early-diagnosis and the later-diagnosis groups differed from the non-ASD group in communication, joint attention, and behaviour regulation (Landa et al., 2007). Compared to the non-ASD group, the early and later-diagnosed groups had fewer consonant sounds, words, and word combinations, fewer gestures, and demonstrated less shared positive affect (Landa et al., 2007).

Repetitive and stereotyped behaviours in children with ASD were traditionally thought to be less common in very young children and more often to appear around the age of 4 to 5 years (e.g., Moore & Goodson, 2003, Charman et al., 2005). However, a recent study by Watt, Wetherby, Barber, and Morgan (2008) found that children later diagnosed with ASD had significantly higher frequencies and durations of repeated and stereotyped behaviours between the ages 18 to 24 months compared to matched groups of children with either developmental disabilities or typical development. In addition, children later diagnosed with ASD repetitively banged or tapped objects on surfaces, rocked or flipped objects back and forth, repeatedly swiped objects off surfaces, spun or rolled objects, placed objects in a stereotypical manner or place, and/or clutched objects for longer periods of time than did the comparison groups (Watt et al., 2008). The children later diagnosed with ASD were also distinguished from the comparison groups by a subset of body movements that included repetitively banging body parts on a table, repetitively rubbing their body, and/or stiffening or posturing of their hands and fingers (Watt et al., 2008). Further, early repetitive, stereotypical behaviour in this study also predicted the severity of ASD symptoms when the children were 36 months of age (Watt et al., 2008). Ozonoff et al. (2008) found similar results in a prospective study examining object exploration behaviour in 66 twelve-month-old children. Nine of the children were later diagnosed with ASD and these children displayed significantly more spinning, rotating, and unusual visual exploration at 12 months compared to the other children (Ozonoff et al., 2008). Repetitive behaviours at 12 months of age predicted cognitive status and severity of ASD symptoms at 36 months (Ozonoff et al., 2008).

Stability and reliability of diagnosis. Recent studies have demonstrated that a diagnosis of ASD at the age of 2 years is stable over time and reliable across clinicians (e.g., Cox et al., 1999; Lord, 1995; Kleinman et al., 2008; Moore & Goodson, 2003; Stone et al., 1999; Turner et al., 2006). Cox et al. (1999) examined the stability of the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and clinical diagnosis in a sample of 50 prospectively assessed children at 20 months and 42 months of age. Closely linked to ICD-10 and the DSM-IV criteria, the ADI-R is a clinician administered, semi-structured parent interview evaluating communication, social development, play, and restricted, repetitive, and stereotyped behaviour (Lord et al., 1994). The ADI-R provides a classification of either Autistic Disorder or non-autistic; it does not provide a classification for any other sub-type (e.g., PDD.NOS) (Pandey et al., 2008). Cox et al. (1999) found that all the children classified with Autistic Disorder using the ADI-R at 20 months of age went on to receive a diagnosis of Autistic Disorder or another Pervasive Development Disorder at 42 months (Cox et al., 1999)

Similarly, Moore and Goodson (2003) followed 20 children (16 diagnosed with Autism, 3 diagnosed with Atypical Autism, 1 diagnosed with Turner Syndrome) from 2 years of age to 4 to 5 years of age. Fourteen of the 16 children diagnosed with Autism at age 2 years retained their diagnosis at assessment at 4 to 5 years of age; the two remaining children moved to a diagnosis of Atypical Autism (Moore & Goodson, 2003). Two of the three children originally diagnosed with Atypical Autism moved to a diagnosis of Autism at follow-up, with the third child retaining the original diagnosis (Moore & Goodson, 2003). The child originally diagnosed with Turner Syndrome retained the diagnosis at follow-up, although the child fell within the Atypical Autism

category (Moore & Goodson, 2003). The findings of this study, similar to those of Cox et al. (1999), suggest that diagnosis of ASD at 2 years of age is stable, although specific diagnoses may be less accurate (Moore & Goodson, 2003).

Building on evidence from studies investigating the stability of ASD diagnosis over the preschool years, Charman et al. (2005) examined the stability of ASD diagnosis for 26 children originally diagnosed at 2 years of age and later reassessed at 7 years of age. Based on clinical judgement, 22 of the children originally diagnosed with Autism retained the diagnosis, three children met criteria for Atypical Autism, and one child no longer met criteria for an ASD (Charman et al., 2005). Charman et al. (2005) noted that the child no longer meeting ASD criteria at 7 years of age had an older sibling with a diagnosis of Autism and suggested this might have influenced the child's parents to over-report symptoms.

Turner, Stone, Pozdol, and Coonrod (2006) examined the stability of the diagnoses of 25 children diagnosed with Autism or PDD-NOS at 2 years of age. Based on clinical judgement and the Autism Diagnostic Observation Schedule- Generic (ADOS-G, Lord et al., 2000) 22 of the 25 children remained on the autism spectrum at 9 years of age (Turner et al, 2006). The ADOS-G is a semi-structured, standardized assessment administered according to expressive language level. Closely linked to ICD-10 and the DSM-IV criteria, the ADOS-G consists of a set of planned interactions that encourage communication, social interaction, and imaginative play (Lord et al., 2000). Diagnostic classification is based on exceeding cut-off scores in three domains: communication, social, and combined social and communication (Lord et al., 2000). Children are

classified as having Autistic Disorder, PDD-NOS, or as being non-autistic (Lord et al., 2000).

On a larger scale, Lord et al. (2006) examined 172 children referred for evaluation at 2 years of age and re-assessed at 9 years of age. At age 2, 130 of the children were given a diagnosis of ASD (84 with Autism, 46 with PDD-NOS). The remaining 42 children did not receive an ASD diagnosis although some were later diagnosed with other developmental delays (Lord et al., 2006). At 9 years of age, 135 children were given a diagnosis of ASD (100 with Autism, 35 with PDD-NOS, and 37 non-ASD) (Lord et al., 2006).

Overall, these studies support the feasibility of identifying children with ASD between 18 and 36 months of age. Further, the diagnosis of Autistic Disorder between 2 and 3 years of age is relatively stable and reliable, although diagnoses of other Autism Spectrum Disorders (e.g., PDD-NOS) are less stable.

Benefits of Early Diagnosis

Early intervention. One of the most compelling reasons for early diagnosis is that it allows for early intervention. The Canadian Paediatric Society (2004) stated in a position statement that intensive behavioural interventions early in life could lead to positive outcomes for children with ASD. There is some evidence to suggest that intervention before 3 ½ years of age has a greater impact on future outcome than intervention begun after 5 years of age (Harris & Handleman, 2000). Harris and Handleman (2000) followed up on the educational placement of 27 children with ASD who had participated in a treatment program using applied behavioural analysis. They found that children entering the treatment program before 4 years of age had higher IQs

at discharge than children who entered the program later (Harris & Handleman, 2000). They also found that children admitted to treatment before 4 years of age were more often placed in regular classroom settings 4 to 6 years later compared to children beginning treatment later (Harris & Handleman, 2000). Overall, all of the children showed measurable gains in IQ, supporting the efficacy of the treatment program (Harris & Handleman, 2000).

Turner et al. (2006) found similar outcomes in a sample of children diagnosed at age 2 and later reassessed at 9 years of age. After dividing the sample into high and low outcome groups based on cognitive scores at age 9, Turner et al., (2006) found that, compared to the lower outcome group, children in the higher outcome group had been diagnosed at earlier ages and had received more hours of speech-language therapy between the ages of 2 and 3 years.

Early intervention can also reduce challenging behaviours, which are a particular risk for young children with ASD (Horner et al., 2002). After an extensive review of behavioural interventions for children with ASD, Horner et al. (2002) noted that once challenging behaviours become integrated into a child's behavioural repertoire, the behaviours were not likely to decrease without some sort of intervention (Horner et al., 2002). Because challenging behaviours can be detrimental to educational, social, and community opportunities, early intervention to minimize challenging behaviours is very important (Horner et al., 2002).

Support for the family. Early identification of ASD can be beneficial to the families of children with ASD. In a postal survey of 494 parents of children with ASD, early diagnosis was a key contributor to reduced parental stress (Mansell & Morris,

2004). Seventy-five percent of the parents agreed that having the diagnosis provided relief and a better understanding and acceptance of their children's behaviour (Mansell & Morris, 2004). Two thirds of the parents reported that having the diagnosis allowed them to access practical help and to better adapt family life to their children's behaviours (Mansell & Morris, 2004). Parents at a focus group reported feeling relief that their suspicions had been validated, and that they were not "mad" or "paranoid" (Osborne & Reed, 2008). Having the diagnosis relieved the distress of being labelled a "bad mother" and being blamed for their children's behaviours (Osborne & Reed, 2008). Parents also reported relief because they were able to explain their children's behaviours to other people and commented on the increase in understanding they received as a result (Osborne & Reed, 2008).

The primary goal of intervention is to maximize children's ability to function independently (Myers, Johnson, & the Council on Children with Disabilities, 2007). Intervention has the potential to minimize the core characteristics of ASD, facilitate the development of learning, promote socialization, and minimize challenging behaviours (Meyers et al, 2007). Overall, intervention has the potential to improve children's quality of life, and to educate and support the lives of their families (Meyers et al., 2007).

Brain plasticity. Recent advancements in the understanding of early brain plasticity support the idea that early intervention increases positive outcome for children with ASD (Dawson, 2008). The development of social and language brain circuitry results from the interaction between an infant's brain and its social environment (Dawson, 2008). For young children with ASD, genetic and environmental risk factors contribute to an atypical trajectory of brain and behavioural development (Dawson,

2008). Young children with ASD engage in less social interaction, leading to decreased social and linguistic input that hinders the typical development of social and linguistic brain circuitry (Dawson, 2008). Effective interventions during early sensitive periods could mediate the effects of early susceptibilities on later outcomes (Dawson, 2008). Thus, early intervention may alter the atypical developmental trajectory of young children with ASD by guiding brain development back to a more typical pathway (Dawson, 2008). The potential impact of early intervention on normal brain development of young children with ASD is a compelling argument for early identification.

Parental Initial Concerns

Parents are often the first to be concerned about their children's development, with the majority of concerns beginning during the first two years of life (Baghdadli et al., 2003; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Samms-Vaughan & Franklyn-Banton, 2008). Initial concerns often involve language delays, abnormalities in social development, and challenging behaviours, leading parents to become anxious and to begin to seek answers for their concerns (Chawarska et al., 2007; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Samms-Vaughan & Franklyn-Banton, 2008; Young et al., 2003).

Howlin and Moore (1997) surveyed 1,295 parents belonging to autism societies in the United Kingdom about their initial concerns regarding their children and their experiences seeking a diagnosis. Children were an average of 20.4 months of age when their parents first became anxious about their development (Howlin & Moore, 1997). Parents waited an average of six to seven months before seeking professional help, although 23% waited almost a year, and 9.3 % waited almost two years (Howlin &

Moore, 1997). When asked about their initial major concern, 40 % of parents reported language issues, almost 20% reported atypical social development, and approximately 13% reported challenging behaviours (Howlin & Moore, 1997). Three percent of the parents were not concerned about their children's development until a professional expressed concern (Howlin & Moore, 1997).

De Giacomo and Fombonne (1998) found similar results in a sample of 82 families referred to an outpatient diagnostic service. Children were, on average, 19.1 months of age when their parents first became concerned, with approximately 30% of the parents becoming concerned by their children's first birthday and 80% by the second birthday (De Giacomo & Fombonne, 1998). Parents waited five months on average before seeking professional advice, with health visitors (Britain) and general practitioners being the first professionals consulted by the majority of parents (De Giacomo & Fombonne, 1998). Parents were more likely to seek help earlier if cognitive impairment was present, there was a concern about a medical problem or a delayed developmental milestone, or there was an older sibling in the family (De Giacomo & Fombonne, 1998). As in the Howlin and Moore study, language and speech development (53.7%) and socio-emotional development (17.1%) were the first concerns noted by many of the parents (De Giacomo & Fombonne, 1998). Fewer parents first became concerned about challenging behaviour (9.8%), autistic-like behaviour (3.7%), or a medical problem or a delay in developmental milestone (11%) (De Giacomo & Fombonne, 1998).

Similarly, in a study aimed at identifying early behavioural abnormalities in children later diagnosed with ASD, Young, Brewer, and Pattison (2003) found, on average, parents first noticed developmental abnormalities when their children were 15.1

months of age but waited an average of 11.7 months before seeking professional help. As in previous studies, delayed language was the most frequently reported concern (77.8%) (Young et al., 2003). Some parents also reported being concerned about poor socialization (29.6%) as well as challenging behaviours (28.4%) such as tantrums or crying (Young et al., 2003). A small number of parents became concerned when their children were 9 to 10 months of age, reporting lack of interest in toys, lack of shared enjoyment, and lack of eye contact as initial concerns (Young et al., 2003).

More recently, Chawarska et al. (2007) examined children's age at the time their parents recognized early developmental abnormalities. The average age of parental concern was 14.7 months with language development and social relatedness being the most frequently reported concerns (Chawarska et al., 2007). In addition, medical problems, developmental delays, and autistic-like stereotyped behaviours were frequent concerns of parents of children later diagnosed with Autistic Disorder, while problems with sleeping, eating, and activity level were more frequently reported as concerns of children later diagnosed with PDD-NOS (Chawarska et al., 2007).

A Canadian study of 56 families with children with ASD, designed by Siklos and Kerns (2007) to replicate Howlin and Moore's (1997) study found similar results. Parents reported becoming concerned about their children's development at 23 months of age, with 88% of the parents reporting concerns before their children were 3 years-old (Siklos & Kerns, 2007). As in previous studies, many parents were first concerned about delays or abnormalities in their children's language development (20.2%), and their social development (20.7%) and waited an average of 5-6 months before seeking professional help (Siklos & Kerns, 2007).

Samms-Vaughan and Franklyn-Banton (2008) surveyed 117 mothers of children diagnosed with autism at the University Hospital in the West Indies. Similar to studies in the United Kingdom and North America, children were on average 21.3 months of age when their mothers first became concerned. Mothers reported being most concerned about their children's language development (85%), behaviour (14.4%), and social skills (9.9%).

Process of Seeking a Diagnosis

The process of seeking help and ultimately obtaining a diagnosis of ASD for their children can be very stressful for parents (Brogan & Knussen, 2003; Goin-Kochel, Mackintosh, & Myers, 2006; Howlin & Moore, 1997; Siklos & Kerns, 2007). Parents often have concerns about their children's development long before they receive a formal diagnosis (e.g., Baghdadli et al., 2003; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997). The first professional that parents turn to for an answer is often a general practitioner or health visitor (Howlin & Moore, 1997; Osborne & Reed, 2008). In Britain, a health visitor is a registered nurse specialized in community health, including child health and health promotion and education (healthvisitor.com, 2009). In many cases, general practitioners do not have the experience to diagnosis ASD (Mandell, Novak, & Zubritsky, 2005). Many parents experience frustration and uncertainty because professions often dismiss their concerns about their children's behaviour, telling them there is "no need to worry", or "he'll grow out of it" (Howlin & Moore, 1997; Maurice, Mannion, Letso, & Perry, 2001). Numerous referrals and long wait-lists for appointments also add to the frustration and stress of obtaining a diagnosis (Mandell et al., 2005).

Age at diagnosis. In their study in which they investigating parents' experiences of the diagnostic process, Howlin and Moore (1997) found the average age of children at final diagnosis of ASD was 6.1 years. Only 8% of the children were diagnosed at their first professional consultation with over half referred to another professional (Howlin & Moore, 1997). A quarter of the families were told there were "no problems" and "not to worry"; 6.5% of these families were told to return if their worries persisted, and 4.2 % were told their children would "grow out of it" (Howlin & Moore, 1997). The majority of families went on to see three or more professionals before obtaining a final diagnosis (Howlin & Moore, 1997). Of the 1,295 families in the study, 1,266 (98%) children eventually received diagnoses of ASD (Howlin & Moore, 1997). In a further study with 770 families in the UK, children with Autistic Disorder were diagnosed around 5.5 years; children with Asperger's Disorder were diagnosed much later, on average at 11 years of age (Howlin & Asgharian, 1999).

More recently, Mandel, Novak, and Zubritsky (2005) surveyed 969 parents of children with ASD to identify factors that may delay diagnosis. Children with Autistic Disorder were diagnosed at age 3 years, 1 month on average, children with PDD-NOS at 3 years, 11 months, and children with Asperger's Disorder at 7 years, 2 months (Mandel et al., 2005). These results suggest recent decreases in the average age at diagnosis compared to previous research (Mandel et al., 2005).

In their sample of Canadian families with children with ASD, Siklos and Kerns (2007) found the average age of children at final diagnosis was 5 years. The majority of families received the final diagnosis from either a clinical psychologist (30.9%), or a paediatrician (30.9%), while others obtained the diagnosis from a child psychiatrist

(13.2%) or a multidisciplinary team (19.1%) (Siklos & Kerns, 2007). Many families (42%) had to travel to another city to obtain a diagnosis and over 60% of the families saw four or more professionals prior to obtaining a diagnosis of ASD (Siklos & Kerns, 2007). Overall, families saw an average of 4.5 professionals and waited an average of 2 years 8 months from when they first sought help to when they obtained a final diagnosis (Siklos & Kerns, 2007). It is of interest to note that girls took an average of 2 years longer to obtain a diagnosis following their first visits to a professional than did boys, even though they did not differ significantly in the number of professionals seen during the process (Siklos & Kern, 2007). Girls were also diagnosed at later ages (6 years, 1 month, on average) than were boys (4 years, 8 months), suggesting that health care specialists give less consideration to the diagnosis of ASD for girls with social, language, and other developmental delays as they would for boys (Siklos & Kern, 2007).

Other factors affecting timing of diagnosis. Mandel et al. (2005) examined other factors affecting the diagnostic process and found that children living in rural areas were diagnosed an average of 5 years later than those living in urban areas (Mandel et al., 2005). Those seeing four or more primary care professionals obtained a diagnosis 6 months later than others did, while children whose paediatricians referred them to a specialist were diagnosed 3.6 months earlier (Mandel et al., 2005). Further, compared to the other children, children with severe language deficits received a diagnosis 1 year, 2 months earlier (Mandel et al., 2005). Greater severity of cognitive impairments has also been associated with earlier age of identification (Chawarska et al., 2007). In an internet survey of 494 families of children with ASD, Goin-Kochel, Mackintosh, and Myers (2006) found higher levels of parental education and higher family income were

associated with earlier diagnosis. Sices, Feudtner, McLaughlin, Drotar, and Williams (2004) surveyed family practice physicians and paediatricians to examine how these professionals manage young children with possible developmental delays. After controlling for differences in age, training, and community size, female physicians were found to provide more screening and to make more referrals for further assessment than were male physicians (Sices et al., 2004). In addition, paediatricians were more likely to make referrals for further assessment than were family physicians (Sices et al., 2004).

Health Belief Model

The Health Belief Model (HBM) is a theoretical model that describes health-related behaviours and medical decision-making. The HBM was originally developed in the 1950s to explain why people did not participate in preventive disease programs (Rosenstock, 1974; Janz & Becker, 1984). The model has since been applied to explain a variety of patient behaviours including factors related to compliance to dieting in obese children, factors associated with skin cancer prevention, and parental motivation to enrol in parenting skills programs (Glanz, Lew, Song, & Cook, 1999; Spoth & Redmond, 1995; Uzark, Becker, Dielman, Rocchini, & Katch, 1988). While the HBM has generally been thought to apply to an individual's own health behaviour, it has also been extended to explain how parents' beliefs and actions predict how they protect their children's health (Glanz et al., 1999).

Derived from a well-established body of psychological and behavioural theories, the HBM extends the approach of associating health behaviours with demographic factors, such as age and gender, and emphasizes the role of personal perceptions (Rosenstock, 1974; Janz & Becker, 1984). In general, the HBM posits that an individual

will take action to avoid, screen for, or control ill-health if they believe that: they are susceptible to a condition, the condition has potentially serious consequences, a course of action will help to reduce either the susceptibility or the seriousness of the condition, and anticipated barriers or costs of taking the action will be outweighed by the benefits (Rosenstock, 1990).

The HBM consists of three dimensions: (1) Perceived Threat, a combination of perceived susceptibility to, and the perceived severity of the health problem (2) Outcome Expectation, a cost-benefit analysis of the perceived barriers in taking a particular action and the benefits of the action, and (3) Self-efficacy Expectation, the belief that one has the ability to accomplish the action (Rosenstock, Stretcher, & Becker, 1988). In addition, the model also proposes that cues-to-action may trigger the decision-making process. These cues can be internal (e.g., symptoms) or external (e.g., mass media communications, interpersonal interactions) (Janz & Becker, 1984). Parents of children with ASD might be cued-to-action by internal cues such as feelings of severe stress over their children's challenging behaviours or external cues such as a flyer on early signs of ASD. Finally, the model also assumes that other diverse demographic, socio-physical, and structural factors might affect the individual's perceptions and thus their health-related behaviour (Janz & Becker, 1984).

Parents' perceptions of the likelihood of their children having ASD is an example of the HBM component *perceived susceptibility*, and parents' perceptions of the consequences (i.e., impact) of having ASD on their children's future outcome is an example of the HBM component *perceived seriousness*. These two components combine to form the dimension termed the *perceived threat* of the health condition (Rosenstock,

1990). Although the perceived threat drives parents toward taking action, it does not define what course of action parents will take (Rosenstock, 1990). Parental judgements of the perceived barriers and the perceived benefits of the action define the course of action taken; these two components together form the dimension *outcome expectations* (Rosenstock, 1990). Parents' perceptions of the costs involved in seeking a diagnosis (e.g., time, money, social stigma, not knowing who to contact, wait lists, etc.) pertain to the component entitled *perceived barriers*. The *perceived benefits* component of the HBM pertains to the extent to which parents see a particular action as beneficial in improving the developmental outcome of their children with ASD. If the perceived benefits of an action are judged greater than the perceived barriers (outcome expectation), than the likelihood of the parent taking that particular action is high.

If parents are concerned about their children's behaviour and establish that there is a perceived threat, the next step in the diagnostic process is consulting with professionals about the concerns. It is at this point that parental self-efficacy may play a significant role in the early identification of children with ASD. The concept of self-efficacy expectation, believed to be distinct from outcome expectation, was incorporated into the HBM theory to increase its explanatory power (Rosenstock, Stretcher, & Becker, 1988). Bandura (1982) defined self-efficacy as the expectation that one can successfully perform a behaviour. He argued that expectations of self-efficacy are the most powerful determinants in behavioural change because self-efficacy expectations determine peoples' initial decision to perform behaviour, the effort they expend, and their persistence (Bandura, 1982). People who have had a variety of successful experiences may have positive self-efficacy expectancies in a greater variety of situations than people

do with limited experiences of success (Sherer & Maddox, 1982). Thus, parents' previous experiences with success and failure may result in a general set of expectations that influence their expectancies of their ability to master new situations (Sherer & Maddox, 1982). It is possible that parents' general self-efficacy expectations may play a role in their decision-making process as they pursue answers for concerns about their children's development and ultimately obtain an early diagnosis of ASD.

Therefore, the HBM may help to explain the actions parents take when they perceive there is a threat to their children's development and future outcome. The beliefs and attitudes they hold about the potential threat and its severity, the weighing of the benefits and barriers of actions, and level of general self-efficacy may be contributing factors toward achieving an early diagnosis of ASD for their children.

In addition to the HBM, other behaviour models that involve attitudes and beliefs have evolved from social and developmental psychology and have been adapted to help explain decision-making behaviour involving health (Galanter & Patel, 2005). These include Social Cognitive Theory (Bandura, 1986) originally called Social Learning Theory (Bandura, 1986) and the Theory of Reasoned Action (Ajzen & Fishbein, 1980). Social Cognitive Theory (Bandura, 1986) suggests that one's beliefs on how the consequences of the behaviour influence the outcome (i.e., outcome perception), one's perception of the benefits of performing the behaviour, and one's belief in their competency to perform the behaviour (i.e., self-efficacy) will determine the occurrence of a particular behaviour. According to Social Cognitive Theory, only when one's belief in their competency to perform the behaviour is high, will certain behaviours occur. As previously mentioned, aspects (e.g., self-efficacy) of Social Cognitive Theory have been

incorporated into the HBM theory to increase its explanatory power (Rosenstock, Stretcher, & Becker, 1988). The Theory of Reasoned Action (Ajzen & Fishbein, 1980) suggests that behaviours are determined primarily by intentions, although the theory acknowledges that intentions are not always predictive of behaviours. Intentions are formed from attitudes of behavioural alternatives (i.e., one's belief about the advantages and disadvantages of potential behaviours) and normative influences (i.e., one's perception of what others think one should do) (Ajzen & Fishbein, 1980). All three theoretical models offer ways of predicting health-related behaviours although Social Cognitive Theory (Bandura, 1986) and the Theory of Reasoned Action (Ajzen & Fishbein, 1980) place more emphasis on social influences, while the HBM focuses more on perceived risks and fears (Murray-Johnson et al., 2006).

Methodological Issues and Limitations in Past Research

Previous researchers have found several commonalities in parents' initial concerns and process of obtaining professional help. For example, researchers have identified barriers that delay the process from when parents first become concerned about their children's development to when they actually obtain a diagnosis; yet relatively little is known about what helps parents obtain an early diagnosis for their children. Previous research has also focused on child-related characteristics such as cognitive ability and severity of ASD symptoms (e.g., Mandell et al., 2005). There is limited research on potential parent variables related to obtaining early diagnosis of ASD for their children. The present study examined what worked for parents as they sought a diagnosis, and parent factors (e.g., attitudes and beliefs) that could have influenced their help-seeking decisions and actions, thereby adding to existing empirical knowledge.

The collection of information regarding the timing of parental initial concerns, the type of first symptoms of ASD, and parent's experiences throughout the diagnostic process often takes place years after the events actually occurred (e.g., De Giacomo & Fombonne, 1998; Goin-Kochel et al., 2006; Howlin & Asgharian, 1999; Howlin & Moore, 1997; Mandell et al., 2005; Siklos & Kerns, 2007). Although the present study was retrospective, it limited the time lapse between the initial events and collection of information by restricting participation to parents of children with ASD under the age of 6 ½ years. This restricted the age-range of children, thereby eliminating the large age range of children followed in previous studies (e.g., Goin-Kochel et al., 2006; Howlin & Asgharian, 1999; Howlin & Moore, 1997; Mandell et al., 2005; Siklos & Kerns, 2007).

Purpose of the Current Research

The purpose of the present study was to identify factors that influenced parents toward obtaining an early diagnosis of ASD for their children. Research has demonstrated that children diagnosed with ASD prior to 30 months of age have more positive outcomes (e.g., Turner et al., 2006) than children diagnosed at later ages, therefore early diagnosis is desirable to maximize potential positive outcomes for children with ASD.

Although past research suggests the average age of diagnosis is decreasing over time, it is still relatively high, given the importance of early intervention. Guided in part by the HBM, the current research went beyond examining the association between child-related and "external factors" (e.g., symptom severity, family income) and age of diagnosis. This was accomplished by exploring the influence of parent variables in an attempt to attain an understanding of how parental beliefs about their children's atypical

development and delays influenced their pursuit of early diagnosis of ASD. The HBM provided a framework to investigate how parental beliefs about the perceived threat of a potential developmental condition, perceived barriers and benefits, and self-efficacy expectancies may affect a parents' decision to seek help for their child's developmental challenges. Figure 2 below illustrates the conceptual model upon which this study was based. If parents' *threat expectation* was high, that is, they perceived their children to be susceptible to having ASD, and that ASD was a serious threat to future developmental outcome, they were expected to take actions that would lead toward early diagnosis. In addition, *outcome expectation*, parental belief that the benefits of obtaining a diagnosis were greater than the barriers they might encounter, would increase the likelihood of obtaining an early diagnosis. Further, *self-efficacy expectation* would also play a role, with high levels of general self-efficacy and specific self-efficacy (belief that they can get help for their children) predicting early diagnosis. Encounters with *cues*, such as television programs or flyers on ASD would also increase the likelihood of parents seeking help, thus increasing the likelihood of early diagnosis. Other factors would also influence parents' decisions. Higher *social economic status* (education, income) would increase parents' knowledge of child development, increasing their *threat expectation* or their level of *self-efficacy expectation*. It would also influence *outcome expectation* and have an effect on the types of *cues* parents came in to contact. Finally, the *severity of ASD characteristics and symptoms* would influence *threat expectation*, with higher severity of ASD characteristics and symptoms becoming a *cue* to higher *threat*

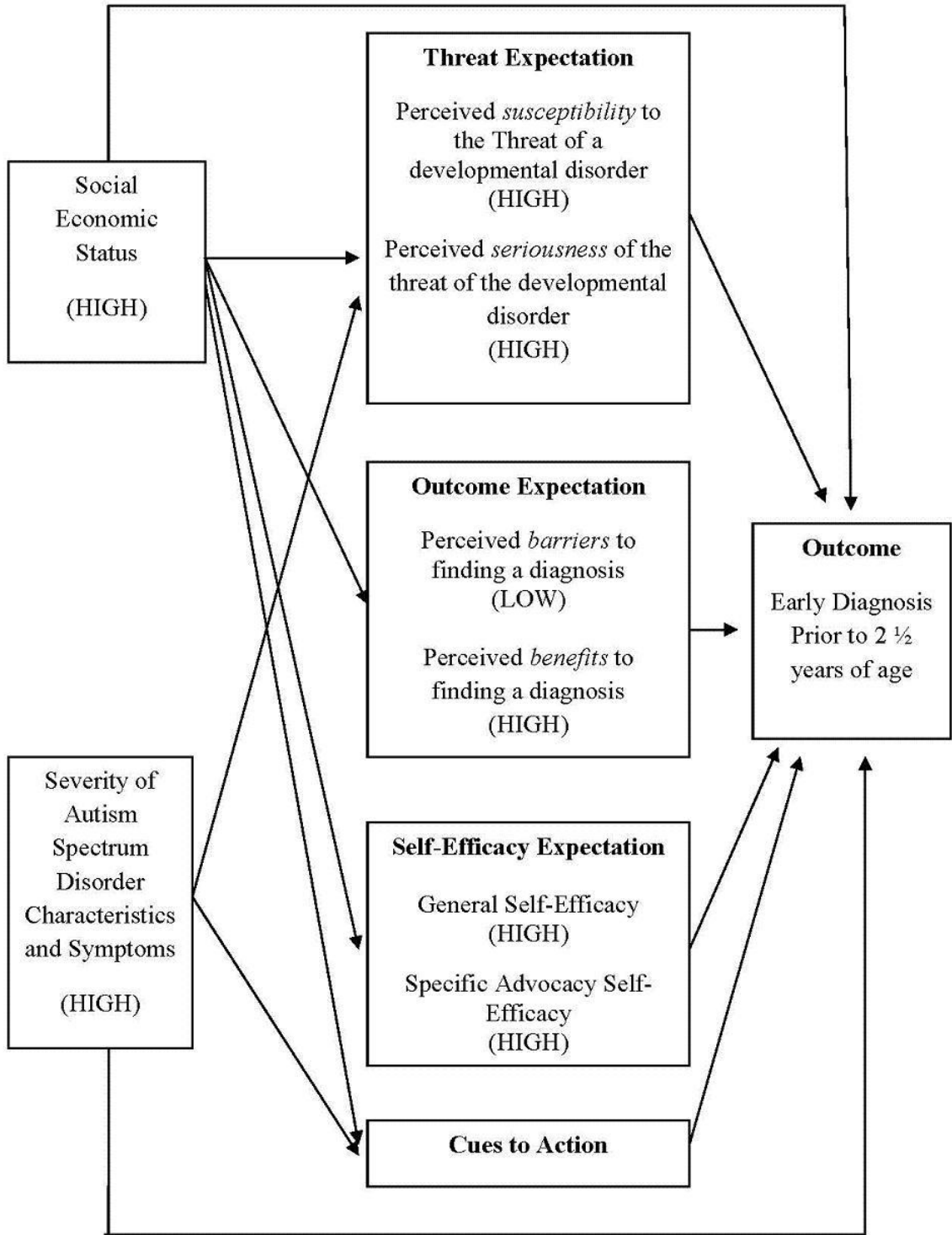


Figure 2. Conceptual model based on the Health Belief Model.

expectation and increasing the likelihood of early diagnosis. This model was used to help explain why some parents successfully obtained diagnoses of ASD when their children were 30 months of age or younger.

This information will facilitate the advancement of knowledge concerning parental factors influencing help-seeking behaviours. A better understanding of parents' beliefs, attitudes, and knowledge of what works for parents as they seek diagnoses for their children could lead to the development of public health workshops or campaigns that help parents in their journey. Finding ways to assist parents in obtaining a diagnosis of ASD as early as possible is important for the development and future outcome of their children with ASD.

Hypotheses

The following hypotheses are based on findings of previous research. It is expected that parents living in Ontario, Canada who participate in this study will be similar in the following ways to parents of children diagnosed with ASD who have participated in studies in countries such as the United Kingdom and the United States.

Hypothesis I: Demographic variables.

1a: Mothers' level of education. It is predicted that higher levels of maternal education will be associated with earlier diagnoses (e.g., Goin-Kochel et al., 2007).

1b: Family income at time of diagnosis. It is predicted that higher levels of income will be associated with earlier diagnoses and that families of children diagnosed with an ASD at or before 30 months will have had a higher income at the time of diagnosis compared to the income of other families in Ontario at that time (e.g., Goin-Kochel et al., 2007).

Hypothesis II: Initial concerns.

2a: Age of child at time of initial concerns. It is predicted that the age of their children at the time of parents' initial concerns will be associated with their children's age at ASD diagnoses such that the earlier the initial concerns, the earlier the diagnoses. (e.g., De Giacomo & Fombonne, 1998).

2b: Age of child at time of initial appointment about concerns. It is predicted that following parents' initial concerns about their children's development, parents of children diagnosed at or before 30 months will have sought professional help for their children sooner compared to parents with children diagnosed with an ASD later than 30 months of age (e.g., De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Siklos & Kerns, 2007).

Hypothesis III. Clinician variables.

3a: Profession of initial clinician. It is predicted that parents of children with an ASD will have first sought help from their family physician or paediatrician rather than other professionals (e.g., Howlin & Moore, 1997; Osborne & Reed, 2008).

3b: Gender of initial clinician. It is predicted that the initial clinician consulted by parents of children with an ASD diagnosed at or before 30 months will have been female compared to parents with children diagnosed with an ASD later than 30 months of age. This general hypothesis is based on research demonstrating gender differences in screening behaviour (e.g., Sices et al., 2003).

3c: Number of professionals consulted. It is predicted that the number of professionals parents sought to get diagnoses of ASD for their children will be associated with earlier diagnoses, such that the fewer professionals sought, the earlier the diagnoses.

It is predicted that parents of children with an ASD diagnosed at or before 30 months will have sought fewer than four professionals compared to parents with children diagnosed with an ASD later than 30 months of age (e.g., Mandel et al., 2005).

Hypothesis IV: Parental perceptions and expectations

It is expected that parents' beliefs and attitudes will predict their help-seeking behaviours. Specifically, compared to parents with children diagnosed with an ASD later than 2 ½ years, parents of children with an ASD diagnosed at or before 30 months will have had at the time of their first initial concerns:

4a: Higher perception of susceptibility to the threat of a developmental disorder.

4b: Higher perception of the seriousness of a developmental disorder.

4c: Higher perception of their knowledge of child development.

4d: Higher perception of their knowledge of ASD.

4e: Higher perception of their ability to decide what help their children need.

4f: Higher perception of their ability to find the help their children need.

4g: Higher perception of their ability to get professionals to take action.

4h: Higher perception of their general self-efficacy.

Exploratory:

Similarities and differences of parents' initial concerns and factors that parents perceived affected their ability to obtain diagnoses of ASD for their children will also be explored.

Chapter II

Method

Participants

Questionnaires were completed by 33 participants. Twenty-two of these participants also completed the In-depth Interview. Because the research was primarily concerned with investigating parental factors that influence early diagnosis, each participant had to be the primary caregiver (e.g., mother, father, legal guardian) of a child with an ASD. In addition, a participant was included only if: (a) the child was 6 ½ years of age or younger at the time the questionnaire was completed; (b) the child had a diagnosis from a qualified clinician (e.g., physician, paediatrician, psychologist, psychiatrist), and c) the family lived in Ontario at the time of the diagnosis. One parent who completed a questionnaire and the In-depth interview had a child who was over the age of 6 ½ at the time of questionnaire completion and another parent lived in Pennsylvania, U.S.A. at the time of the child's diagnosis and these participants were excluded from all analyses. Two additional participants were excluded from all analyses because they did not provide any diagnostic information about their children and as a result, it was not possible to categorize their children in a diagnostic group. The resulting sample consisted of 29 parents.

Questionnaire. The mean age of parents who participated was 33.8 years.

Parents with higher education appear to be over-represented in the current sample compared to the provincial average (Statistics Canada, 2006). Participants reported current family income of under \$25,000 (7%), \$25,000 to \$49,999 (31%), \$50,000 to \$74,999 (3.4%), and \$75,000 and over (41.4%). Four participants (13.8%) preferred not

to report their current family income and data for one participant (3.4%) was missing.

Parents in the current sample appear to have a lower average family income compared to the provincial average (Statistics Canada, 2007).

In-depth Interview. The mean age of parents who participated was 33.3 years of age. Participants reported current income of under \$25,000 income (4.8%), \$25,000 to \$49,999 (38.1%), and \$75,000 and over (47.6%). Two participants (9.5%) preferred not to report their current family income (see Table 1 and Table 2 for demographic information for the Questionnaire participants and the In-Depth Interview participants respectively).

Children. Questionnaires were completed for 29 children (24 boys and 5 girls). The boy-girl ratio of 4.8:1 is consistent with the expected boy-girl prevalence ratio for ASD (APA, 2000). As part of the research procedure, parents were asked to provide their children's diagnostic report. Seventeen diagnostic reports were received representing a 58.6% return rate. Of the reports received, four (23.5%) revealed errors in parent report on age of diagnosis (ranging from 2 to 14 months) and 1 (5.9%) revealed an error in parent report on the actual diagnostic label. Corrections were made to reflect the information from the children's diagnostic reports (see Table 3 for descriptive statistics for participants' children). Regarding birth order, eight children were the youngest in the family, five were in the middle, nine were the oldest children in the family, and six children were the only children in their family.

In-depth Interviews were completed with the parents of 21 children (17 boys and 4 girls). Seventeen children (81%) had Autism or Autistic Disorder, 1 child had Asperger's Disorder (5.9%), 2 children had PDD-NOS (11.8%), and 1 child had a diagnosis of

Table 1

Demographic Characteristics of Questionnaire Participants

Participant Characteristics	Total		Early Dx Group		Later Dx Group	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Gender						
Mothers	25	86.2	11	91.7	14	82.4
Fathers	4	13.8	1	8.3	3	17.6
Marital Status						
Single	4	13.8	1	8.3	3	17.6
Married	24	82.8	11	91.7	13	76.5
Divorced	1	3.4			1	5.9
Educational Status						
High School or Less	2	6.9			2	11.8
Some College/University	6	20.7	1	8.3	5	29.4
College/University Degree	14	48.3	7	58.3	7	41.2
Post-Graduate	6	20.7	3	78.0	3	17.6
Residency						
South Western Ontario	20	69.0	8	66.7	12	70.6
Central Ontario	6	20.7	3	25.0	3	17.6
Eastern Ontario	1	3.4	1	8.3		
Northern Ontario	1	3.4			1	5.9

(Table 1 continues)

(Table 1 continued)

	Total		Early Dx Group		Later Dx Group	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Ethnicity						
White/Caucasian	22	75.9	10	83.3	12	70.6
Arabic	2	6.9			2	11.8
Chinese	1	3.4			1	5.9
Filipino	1	3.4	1	8.3		
Métis	1	3.4			1	5.9
Southeast Asian	1	3.4			1	5.9
First Language						
English	24	82.8	11	91.7	13	76.5
Filipino	1	3.4	1	8.3		
French	1	3.4			1	5.9
Serbian	1	3.4			1	5.9
Vietnamese	1	3.4			1	5.9

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group \geq 30 months.

Table 2

Demographic Characteristics of In-Depth Interview Participants

Participant Characteristics	Total		Early Dx Group		Later Dx Group	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Gender						
Mothers	19	90.5	9	100	10	83.3
Fathers	2	9.5			2	16.7
Marital Status						
Single		14.2			3	25.0
Married		81.0	9	100	8	66.7
Divorced	1	4.8			1	8.3
Educational Status						
High School or Less		4.8			1	8.3
Some College/University		14.2	1	11.1	2	16.7
College/University Degree		57.1	6	66.7	6	50.0
Post-Graduate		23.8	2	22.2	3	25.0
Residency						
South Western Ontario		66.7	6	66.7	8	66.7
Central Ontario		23.8	1	11.1	3	25.0
Eastern Ontario		4.8	1	11.1		
Northern Ontario		4.8			1	8.3

(Table 2 continues)

(Table 2 continued)

	Total		Early Dx Group		Later Dx Group	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Ethnicity						
White/Caucasian		80.9	8	88.9	9	75.0
Arabic		4.8			1	8.3
Chinese		4.8			1	8.3
Filipino		4.8	1	11.1		
Métis		4.8			1	8.3
First Language						
English		95.2	8	88.9	11	91.7
Filipino		4.8	1	11.1		
French					1	8.3

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group \geq 30 months.

Table 3

Diagnostic Information for Children of Participants

Diagnosis	Total		Early Dx Group		Later Dx Group	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Questionnaire (<i>N</i> = 29)						
Autistic Disorder	22	75.9	9	75.0	13	76.5
PDD-NOS	5	17.2	3	25.0	2	11.8
Asperger's Disorder	1	3.4			1	5.9
Autism Spectrum Disorder	1	3.4			1	5.9
In-Depth Interview (<i>N</i> = 21)						
Autistic Disorder	17	81.0	8	88.9	9	75.0
PDD-NOS	2	11.8	1	11.1	1	8.3
Asperger's Disorder	1	5.9			1	8.3
Autism Spectrum Disorder	1	5.9			1	8.3

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group \geq 30 months.

Autism Spectrum Disorder (5.9%). The sample was predominately White/Caucasian (80.9%), followed by Arab (4.8%), Chinese (4.8%), Filipino (4.8%) and Métis (4.8%).

The majority of children spoke English first in the home (95.2%), however; Filipino was spoken first in one child's home (4.8%).

Recruitment Methods

The present study was approved by the University of Windsor's Research Ethics Board. The researcher posted and distributed recruitment flyers around the Windsor area at several locations frequented by parents as well as an agency that provides resources to families with children with ASD (see Appendix A for a copy of the flyer). Recruitment flyers were also sent via email to all the provincial co-ordinators for the preschool Speech and Language programs in Ontario.

Emails (see Appendix B for a copy of the email) were sent to 22 Autism Ontario Chapters requesting the recruitment flyer be distributed to the members of the chapters. The emails were followed up with telephone calls to the Chapter contact persons. In addition, 10 copies of the questionnaire and recruitment flyer were sent to each of 15 Chapters of Autism Ontario with the request they be forwarded to parents in the area (see Appendix C for a copy of the letter of request).

On-line recruitment flyers (see Appendix D for a copy of the flyer) were posted on-line on The Autism Calendar, the Autism Support Network, and the research link of the Autism Ontario website. The on-line recruitment flyer was also distributed to four autism on-line groups on the AutismOntario Yahoo list-serve.

The researcher asked parents of children who were on the waiting list or receiving treatment at the Summit Centre for Preschool Children with Autism if they would

participate in the research. The Summit Centre offers intensive intervention to children living within one hour of Windsor, Ontario (Summit Centre, 2008). Finally, the researcher attended several functions in which parents of children with autism were present, including a parent support group for parents with children with ASD, an All About Autism parent meeting, a More than Words parent meeting for children with speech and language difficulties, a workshop for parents with children with autism, the annual general meeting of the Windsor-Essex County Chapter of the Autism Society of Ontario, a sports event for children with ASD, and a movie event for children with ASD.

Measures

Help-seeking questionnaire. The original questionnaire was designed for the present research and requested demographic information and information about parents' concerns and their diagnostic experiences (see Appendix E for a copy of the questionnaire).

Demographic information. Demographic information for children of parents who participated in the research included the children's date of birth, gender, first language, ethnicity, and diagnosis. Demographic information for the parents included their age range, gender, first language, ethnicity, marital status, education, employment status, and number of other children in the family.

First concerns. Parents were asked of their first concerns about their children's development. Content for this section of the questionnaire was based on previous studies of early symptoms and behaviours associated with ASD (e.g., Baghdadli et al., 2003; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997). Parents were also requested to provide their children's age at the time parents first became concerned, initial actions

taken because of these concerns, and the professionals consulted because of these concerns. Next, parents were requested to gauge retrospectively their belief in the possibility of their children having a developmental disorder, their knowledge of child development and autism, and their perception of the threat their children's condition could have on future developmental outcomes at the time of parents' initial concerns. The response format for these questions was a 5-point Likert scale ranging from 1 = none to 5 = very (see Appendix E for a copy of the questionnaire). In addition, parents were requested to list other actions they considered taking at the time of their initial concern, perceived barriers to each considered action, and perceived benefits to each considered action.

Diagnosis. Parents were asked to provide their children's age at the time of diagnoses, the professions of the clinicians providing the diagnoses, and the facilities of the clinicians providing the diagnoses (e.g., hospital, private office). An estimate of the time taken to travel to reach the clinician was also requested. Finally, parents were asked for their opinions on the main factors they believed contributed to their children's receiving diagnoses.

Self-efficacy scale (SGSE). Parents were asked to think back to before their children received diagnoses and complete the General Self-Efficacy (GSE) subscale of the Self-Efficacy Scale (SGSE; Sherer et al., 1982). The GSE subscale is a list of 17 statements that measure the expectations an individual has in their ability to achieve a broad range of stressful or challenging demands. Participants are asked to respond to each item on a forced-choice 5-point Likert scale indicating to what extent they agree or disagree with each statement (A = disagree strongly, E = agree strongly). The GSE

subscale was scored by converting the letters to numbers (A = 1, B = 2, etc.). Items marked “R” on the scoring algorithm were reverse scored (A = 5, B = 4, etc.). The items were then summed to produce the GSE subscale score. Higher scores indicated higher general self-efficacy (possible range = 17 to 85). The conversion from letters to numbers, the reverse scoring, and the calculation of the GSE subscale score were checked by the researcher or the trained research assistant.

The SGSE has been one of the most widely used general self-efficacy scales with over 200 published studies having used or cited the scale (Chen, Gully, & Eden, 2001). The GSE subscale has moderate to high internal consistency reliability ($\alpha = .76$ to $.89$) (e.g., Chen et al., 2001; Sherer et al., 1982). A series of studies by Chen, Gully, and Eden (2001) have demonstrated that the GSE has good discriminant and content validity. The content and discriminant validity of the GSE subscale of the SGSE (Sherer et al, 1982) and the Rosenberg Self-esteem Scale (Rosenberg, 1965) were examined by two independent panels (Chen et al., 2001).

The panels were given definitions of general self-efficacy (GSE) and self-esteem and asked to indicate whether the items on each scale represented “GSE” or “self-esteem” (Chen et al., 2001). The first panel sorted 54% of the items on the GSE subscale of the SGSE as “GSE”, 10% as “self-esteem”, and 36% as “other” (Chen et al., 2001). On the Rosenberg Self-esteem Scale, the first panel sorted 7.5% of the items as “GSE” and 92.5% of the items as “self-esteem” (Chen et al., 2001). The second panel sorted 64% of the items on the GSE subscale of the SGSE as “GSE”, 14% as “self-esteem”, and 22% as “other” (Chen et al., 2001).

On the Rosenberg Self-esteem Scale, the second panel sorted 11% of the items as “GSE”, 83% of the items as “self-esteem”, and 6% of the items as “other” (Chen et al., 2001). These results provide some evidence of content and discriminant validity of the GSE subscale and the Rosenberg Self-esteem Scale (Chen et al., 2001). Adequate construct validity has been demonstrated by correlating the subscales of the SGSE with scores of several other measures of personality characteristics (Chen et al., 2001; Sherer & Adams, 1983; Sherer et al., 1982). Moderate negative correlations were expected between scores on the SGSE and the Internal-External Control Scale (I-E; Rotter, 1966), the Personal Control Subscale of the I-E Scale (Gurin, Gurin, Lao, & Beattie, 1969), and the Rosenberg Self-esteem Scale (Rosenberg, 1965). These expectations were met with moderate negative correlations of $r = -.287$, $r = -.355$, and $r = -.510$ respectively (Sherer et al., 1982). Moderate positive correlations were expected between the SGSE and the Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1964), the Ego Strength Scale (Barron, 1953) and the Interpersonal Competency Scale (Holland & Baird, 1968). These expectations were met with moderate positive correlations of $r = .431$, $r = .290$, and $r = .451$ respectively (Sherer et al., 1982). In addition, evidence of criterion validity of the GSE subscale has been demonstrated through the subscale’s ability to predict past success in vocational, educational, and military areas (Sherer et al., 1982).

Three additional questions related directly to parents’ confidence in their ability to perform behaviours to access help for their children were created specifically for this study. “I am confident in my ability to decide what help my child needs,” “I am confident in my ability to find the help my child needs,” and “I am confident in my ability to get professionals to take action to get the help my child needs.” Participants are asked to

respond to each item on a forced-choice 5-point Likert scale indicating to what extent they agree or disagree with each statement. High scores indicate higher expectancies in their confidence (i.e., specific self-efficacy) to get the help they feel their children need (see Appendix E).

In-depth interview. The In-depth Interview (see Appendix F) consisted of six questions presented in an open-ended format to provide further information on parents' initial concerns about their children's development and factors they perceived as having an impact on their ability to obtain a diagnosis of ASD for their children.

Procedures

The questionnaire was available to participants in four formats, a telephone interview format, a face-to-face interview format, a pencil and paper format, and an on-line version (Dillman, Smyth, & Christian, 2009). The rationale for providing the questionnaire in four formats was based on research that suggests parents of children with ASD are more likely to experience higher levels of stress compared to parents of children with other developmental disorders and parents of typically developing children (e.g., Bromley, Hare, Davison, & Emerson, 2004; Davis & Carter, 2008; Hastings & Brown, 2002; Osborne & Reed, 2010). Providing the parents the option of their preferred questionnaire format was designed to minimize any further stress to parents resulting from taking part in the present research.

Further rationale for providing the questionnaire in a face-to-face or telephone interview format provided parents with English as their second language the option of having the questions read to them by the researcher and their answers recorded for them.

Participants recruited by the researcher at functions in which parents of children with ASD were present were given a recruitment flyer (see Appendix A for a copy of the flyer) describing the purpose of the study, asked if they would prefer to complete the questionnaire via telephone, face-to-face, via pencil and paper, or on-line, and asked to provide their contact information (see Appendix G for a copy of the recruitment script). Parents choosing to complete the questionnaire via pencil and paper were provided with a package that contained a stamped, pre-addressed return envelope, a Letter of Information (see Appendix H for a copy of the Letter of Information), a Consent to Participate form (see Appendix I for a copy of the Consent to Participate), a Consent to Release Information form (see Appendix J for a copy of the Consent to Release Information form) that would allow the researcher to request a copy of the child's diagnostic report from the diagnosing clinician, the questionnaire, and a card giving the participant the option of receiving a five-dollar Tim Horton's gift card (see Appendix K for a copy of the Thank You form). Parents choosing the pencil and paper copy of the questionnaire were asked to complete and return the questionnaire within two weeks.

Telephone questionnaire format. Participants who provided contact information for a telephone questionnaire interview were contacted by the researcher to arrange a time to complete the interview (see Appendix L for a copy of the script for booking questionnaires via telephone). At the scheduled interview time, the researcher contacted the participant and followed the telephone questionnaire interview script (see Appendix M for a copy of the script for completing the questionnaire via telephone) to complete the questionnaire. If consent was given, the interview was audio-recorded. Following the completion of the questionnaire, the participant was asked to provide an address to which

a five-dollar Tim Horton's gift card would be mailed as a thank you for participating in the research study, along with a copy of the Letter of Information (see Appendix N for a copy of the Letter of Information), a Consent to Release Information form, and a stamped, pre-addressed return envelope for the participant to use to return the completed Consent to Release Information form. If the questionnaire interview was audio-recorded, the interview was transcribed and checked for accuracy.

Face-to-face questionnaire format. Participants who provided contact information for a face-to-face interview were contacted by the researcher to arrange a time and place for the interview, if not previously arranged (see Appendix O for a copy of the script for booking questionnaires for face-to-face completion). At the time of the face-to-face questionnaire interview, participants were provided with a Letter of Information (see Appendix P for a copy of the Letter of Information), and asked to sign the Consent to Participate form (see Appendix Q for a copy of the Consent to Participate), a Consent to Audio-record form (see Appendix R for a copy of the Consent to Audio-record form) and a Consent to Release Information form. If the participant chose not to have the interview audio-recorded, the researcher copied the participant's answers onto a paper copy of the questionnaire. A script (see Appendix S for a copy of the script for completing questionnaires face-to-face) was followed to complete the questionnaire interview. After completing the questionnaire, participants were given the option to accept a five-dollar Tim Horton's gift card as a thank you and asked if they would be interested in providing further information at a later date in an In-depth Interview via telephone. If the questionnaire interview was audio-recorded, the audio-recording of the interview was transcribed and checked for accuracy.

Pencil and paper questionnaire format. For participants requesting a mail-out copy of the pencil and paper format of the questionnaire, a package containing a stamped, pre-addressed return envelope, a Letter of Information (see Appendix H for a copy of the Letter of Information), a Consent to Release form, the research questionnaire, and a card with the option of receiving a five-dollar gift card as a thank for participating in the research (see Appendix K for a copy of the Thank you form) was mailed to the participant.

Packages of questionnaires sent to the Autism Ontario Chapters included a letter requesting the questionnaire packages be forwarded to parents in their region (see Appendix C for a copy of the letter). A recruitment flyer (see Appendix A for a copy of the flyer) was included with each questionnaire package to allow participants the option of choosing to complete the questionnaire in any of the four questionnaire formats. The researcher contacted each Chapter contact person via email (see Appendix B for a copy of the email) and telephone prior to mailing the packages of questionnaires.

On-line questionnaire format. Participants completing the questionnaire on-line were linked to the on-line version of the Letter of Information and Consent to Participate (see Appendix T for a copy of the Letter of Information and Consent to Participate) once they logged on to the questionnaire website. At the end of the questionnaire, participants were linked to a web page (see Appendix U for a copy of the on-line draw card) giving them the opportunity to enter a draw for a \$50 dollar gift certificate to Tim Horton's, Toy's R Us, or Chapters. Participants were asked to provide their contact information and to check a box if they were willing to provide further information in an In-depth telephone interview.

Summary of formats. Sixteen parents completed their questionnaire on-line (55.2%), 5 via mail (17.2%), 5 via telephone (17.2%), and 3 in person (10.3%). Twenty of the 29 parent participants (69%) completed In-depth interviews via telephone in addition to the questionnaire.

Diagnostic reports. The Consent to Release Information forms completed by the participants were forwarded by mail to the designated diagnosing clinician along with a letter requesting a copy of the child's diagnostic report (see Appendix V for a copy of the letter). Parents were given the option to provide a photo-copy of their children's diagnostic report themselves if they preferred.

In-depth interviews. Participants who completed the questionnaire and indicated they were willing to participate in an In-depth Interview via telephone were contacted to arrange a time to complete the interview (see Appendix W for a copy of the script for booking In-Depth interview). All In-depth interviews were completed via telephone. At the arranged time, the researcher contacted the participant to complete the interview using a telephone script (see Appendix X for a copy of the telephone script). The interview was audio-recorded if consent was provided by the participant. If consent to audio-record was not provided by the participant, the research recorded the interview by hand. Participants were mailed a copy of the Letter of Information (see Appendix Y for a copy of the Letter of Information) and a \$5 Tim Horton's gift card as a thank you for participating in the In-depth Interview. All audio-recordings were transcribed and checked for accuracy.

Participants' responses to the interview questions were analysed by thematic analysis (Attride-Stirling, 2001; Braun & Clarke, 2006). Each interview transcript was

read through and coded for emerging themes. A master list of the codes was created and used for subsequent transcripts, with additional codes added as needed. Transcripts were read and reread by the primary researcher throughout the coding process to aid in understanding the emerging themes. Coded segments of text from the transcripts were extracted and grouped together and checked for emerging patterns. Patterns of coded text were organized into themes and further refined. The resulting themes were organized into coherent groupings creating a thematic network.

Chapter III

Results

The aim of this research study was to identify factors that influence parents toward obtaining an early diagnosis of ASD for their children. Results of the research are presented in several sections. First, descriptive statistics utilizing data from the entire sample and between groups are presented for several variables, including initial concerns, age at initial concerns, age at initial appointment, age at diagnoses, and variables relating to the professionals consulted. Following this, correlational analyses, data screening, and test statistics correlating with the research questions are presented. Finally, analyses conducted on parents' perceptions and opinions on their diagnostic experience will be presented.

The planned analytical procedures related to the research questions included exploring variations in demographic and parental variables using *t*-tests for independent groups and Chi-square analyses. Associations between continuous variables (e.g., age at first concern, age at first appointment, help-seeking delay) and age at first diagnosis were examined using Pearson correlations. Finally, thematic analysis was used to organize and explore the qualitative data. For all analyses, the statistical significance level was set at .05. Unless otherwise noted, all statistical analyses were completed using PASW Statistics, version 18.0 (SPSS Inc., 2010). Qualitative analyses were completed with the assistance of NVIV08, computer software to help organize qualitative data (QSR International, 2007)

Descriptive Statistics

Participants were divided into two groups: a) an early diagnosis group (Early Diagnosis Group); parents with children diagnosed with ASD at or before 30 months of

age and, b) and a later diagnosis group (Later Diagnosis Group); parents with children diagnosed with ASD later than 30 months of age.

Children's age at diagnosis. Parents were asked to indicate the age of their children at the time they were diagnosed with ASD. Overall, the average age of children at the time of diagnoses was 36.03 months ($SD = 12.28$; range = 20 to 61 months). The average age at diagnoses for children diagnosed with ASD at or before 30 months was 25.00 months ($n = 12$; $SD = 2.83$; range = 20 to 30 months). The average age at diagnoses for children diagnosed with ASD later than 30 months of age was 43.82 months of age ($n = 17$; $SD = 10.13$; range = 31 to 61 months).

Overall, 22 of the children (75.9%) were diagnosed with Autism or Autistic Disorder, 1 with Asperger's Disorder (3.4%), 1 with Autism Spectrum Disorder (3.4%), and 5 with Pervasive Development Disorder, Not Otherwise Specified (17.2%).

Initial concern.

Person initially concerned. The majority of parents who completed questionnaires (69%) indicated that they were the first person to become concerned about their children's development. Parents reported that grandmothers (10.3%), other parents (3.3%), family physicians (6.9%), or others (10.3%; speech and language pathologists, staff at Ontario Early Years Centres) first became concerned. Table 4 provides frequency data by Early vs. Later diagnoses group.

Areas of initial concern. Parents were asked to indicate their initial concerns about their children's development. The most common initial concern was with language development (86.2%), followed by behaviour issues (58.6%), social skills (55%), other

Table 4

Frequency Data for Initial Person Concerned by Early vs. Later Diagnoses Groups

First Concerned	Total (N = 29)		Later Dx Group (n = 12)		Later Dx Group (n = 17)	
	N	%	Frequency	%	Frequency	%
Parent Participant	20	69	7	58.3	13	76.5
Grandmother	3	10.3	3	25.0		
Other Parent	1	3.3			1	5.9
Family Physician	2	6.9			2	11.7
Other	3	10.3	2	16.7	1	5.9
Total	29	100.0	12	100.0	17	100.0

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group $>$ 30 months.

concerns (24.1%), and medical concerns and/or delays in milestones (17.2%). Figure 3 provides percentages of parents' initial concerns in each of the developmental areas.

Parent lists of "other concerns" included sensory issues (e.g., to smell, sound, touch), repetitive and stereotypical behaviour (e.g., hand flapping, spinning objects, walking on toes), and odd obsessions and fixations.

The majority of parents (72.4%) were initially concerned in more than one area of development (see Figure 4 for the number of areas of development for parents' initial concerns). An independent-samples *t*-test was conducted to examine differences between the number of areas of concern of parents with children diagnosed with ASD at or before 30 months of age and parents with children diagnosed with ASD later than 30 months of age. There were no significant differences in the number of areas of concern between the Early Diagnosis Group ($M = 2.50$; $SE = 0.34$) and the Later Diagnosis Group ($M = 2.35$; $SE = 0.31$), $t(27) = .317$, $p = > .05$, $r = .06$.

Children's age at initial concern. Parents were asked to indicate the age of their children at the time of their initial concerns about their children's development. Overall, the average age of children at initial concern was 21.03 months ($SD = 8.82$; range = 3 to 44 months). The average age of initial concern for children diagnosed with ASD at or before 30 months of age was 15.92 months ($SD = 6.39$; range = 3 to 24 months). The average age of initial concern for children diagnosed with ASD later than 30 months of age was 24.65 ($SD = 8.63$; range = 12 to 44 months). Table 5 provides information on the frequencies of age at time of initial concern by group.

Children's age at initial appointment. Parents were asked to indicate the age of their children at the time of their first appointment to seek help for concerns about their

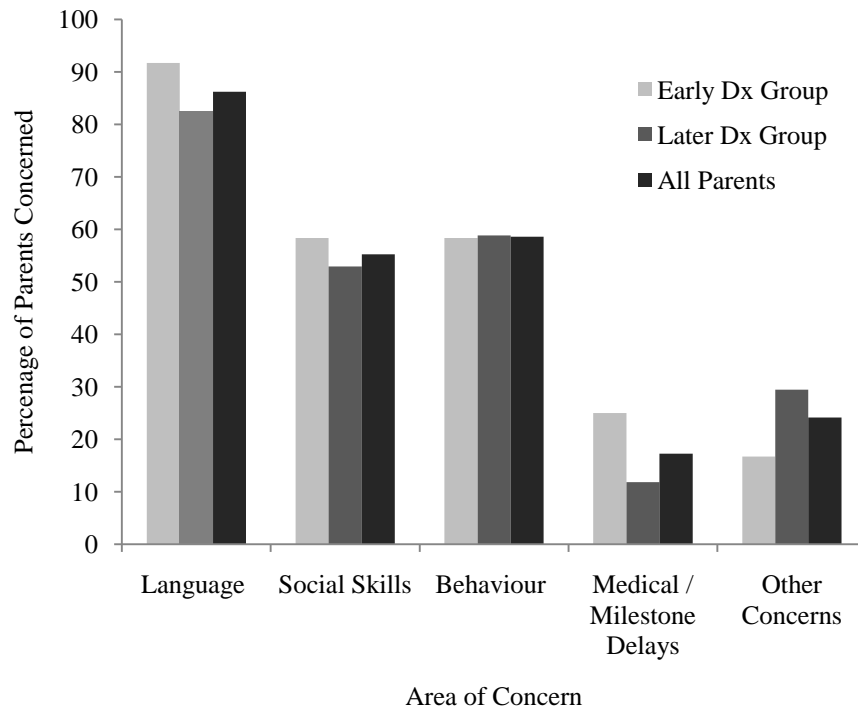


Figure 3. Percentage of parents' initial concerns in each developmental area.

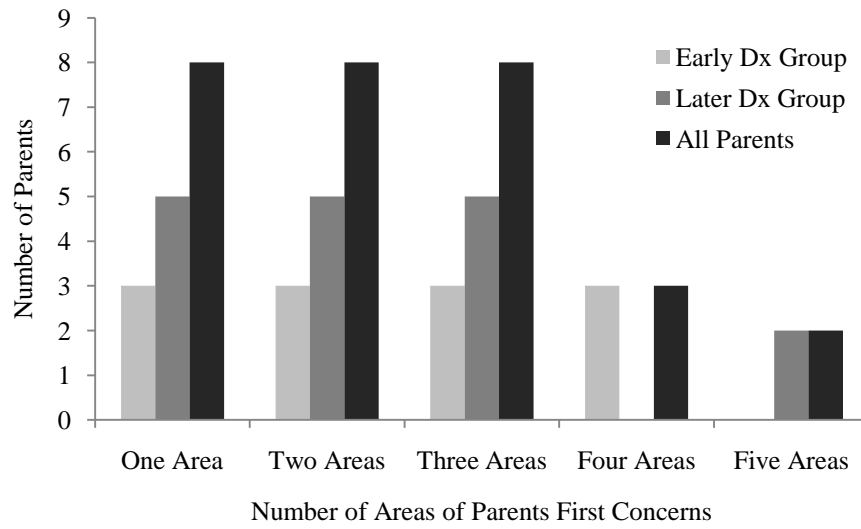


Figure 4. Number of areas of development for parents' initial concerns.

Table 5

Frequency Data for Age at Initial Concern by Early vs. Later Diagnoses Groups

Age (months)	Total (<i>N</i> = 29)	Early Dx Group (<i>n</i> = 12)		Later Dx Group (<i>n</i> = 17)	
	<i>N</i>	Frequency	%	Frequency	%
0 - 6	1	1	8.3		
7 - 12	4	3	25.0	1	5.8
13 - 18	10	5	41.7	5	29.6
19 - 24	7	3	25.0	4	23.6
25 - 30	3			3	17.6
31 - 36	3			3	17.6
37 - 42					
43 - 44	1			1	5.8
Total	29	12	100.0	17	100.0

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group $>$ 30 months.

children's development. Overall, the average age of children at the time of their initial appointment was 25.03 months ($SD = 10.73$; range = 12 to 51). The average age at initial appointment for children diagnosed with ASD at or before 30 months was 18.25 months ($SD = 4.49$; range = 12 to 26 months). The average age at initial appointment for children diagnosed with ASD later than 30 months of age was 29.82 months of age ($SD = 11.34$; range = 12 to 51 months). Table 6 provides information on the frequencies of age at time of initial appointment.

Actions taken at time of initial concern. Parents were asked to report what actions they took when they became concerned about their children's development. Table 7 provides frequencies of actions taken by parents at the time of their initial concern.

Professionals parents consulted. Parents were asked to indicate the professionals they consulted regarding their concerns about their children's development and to indicate the order in which they visited the professionals. Overall, parents reported first consulting family physicians (44.8%), paediatricians (20.7%), neurologists (3.4%) speech and language pathologists (24.1%), or early childhood educators (3.4 %). Parents reporting seeing from 2 to 7 professionals ($M = 4.07$, $SD = 1.44$) before obtaining diagnoses for their children.

Parents were asked to indicate the profession of the person who referred them to the diagnosing clinician. Overall, parents reported the referring clinician to be a speech and language pathologist (37.9%), paediatrician (31%), occupational therapist (20.7%), psychologist (6.9%), or a family physician (3.4%). Table 8 provides frequency and descriptive information about the initial professionals and the referring professionals parents consulted.

Table 6

Age at Initial Appointment by Early vs. Later Diagnoses Groups

Age (months)	Total (<i>N</i> = 29)	Early Dx Group (<i>n</i> = 12)		Later Dx Group (<i>n</i> = 17)	
	<i>N</i>	Frequency	%	Frequency	%
12 - 18	12	8	66.6	4	23.6
19 - 24	5	2	16.7	3	17.6
25 - 30	4	2	16.7	2	11.8
31 - 36	4			4	23.6
37 - 42	1			1	5.8
43 - 48	2			2	11.8
49 - 51	1			1	5.8
Total	29	12	100.0	17	100.0

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group $>$ 30 months.

Table 7

Actions Taken by Parents at Time of Initial Concern

Initial Actions Taken	<i>N</i>	%
Contacted family physician	19	65.5
Other	14	48.3
Contacted speech and language professional	9	31.0
Talked to someone at Early Years or similar program	9	31.00
Contacted audiologist	7	24.1
Talked to friend about concerns	6	20.7
Talked to child's educational staff	1	3.4

Note: Some parents took more than one action
N = 29

Table 8

Initial and Referring Professionals Consulted by Early vs. Later Diagnoses Groups

	Total (N = 28)		Early Dx Group (n = 12)		Later Dx Group (n = 28)	
	N	%	n	%	n	%
First Professional Consulted						
Family Physician	13	44.8	5	41.7	8	47.1
Paediatrician	6	20.7	3	25.0	3	17.6
Speech and Language						
Pathologist	6	20.7	5	36.7	3	17.7
Neurologist	1	3.4			1	5.9
Early Childhood Educator	1	3.4			1	5.9
Profession of Referring Clinician						
Speech and Language						
Pathologist	11	37.9	6	50.0	5	29.4
Paediatrician	9	31.0	1	8.3	8	47.1
Occupational Therapist	6	20.7	3	25.0	3	17.6
Psychologist	2	6.9	1	8.3	1	5.9
Family Physician	1	3.4	1	8.3		

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group $>$ 30 months.

Fifty-nine percent of parents reported obtaining the diagnoses for their children from clinicians affiliated with agencies (i.e., agencies providing support and services for children with medical or developmental issues). Parents also obtained diagnoses for their children from clinicians working in private practices (20.7%), private clinics (6.9%), or hospital clinics/offices (10.3%). Sixty-two percent of the diagnosing clinicians were psychologists, followed by paediatricians (20.7%), psychiatrists (10.3%), and family physicians (3.4%). While the majority of parents reported not having to pay a fee (82.8%), some parents reported paying a fee for their children's diagnoses (13.8%). Table 9 provides frequency and descriptive information about the diagnosing professional.

Correlational Analyses

Pearson correlations were conducted between continuous variables, including age at initial concern, help-seeking delay (i.e., delay in months between initial concern and first appointment), age at initial appointment, age at diagnoses, and family income at time of diagnosis for the entire sample (see Table 10), and for both the Early Diagnosis Group (see Table 11), and the Later Diagnosis Group (see Table 12). For the entire sample, there were significant correlations between children's age at initial concern about development and children's age at the time of the initial appointment to address the concerns, $r = .85, p < .001$ and children's age at the time of the diagnosis, $r = .67, p < .001$. Significant correlations were also found between delay in help-seeking and children's age at the time of the initial appointment to address the concerns, $r = .56, p < .01$ and children's age at the time of the diagnosis, $r = .54, p < .01$. Pearson correlations also indicated a significant relation between children's age at the time of initial appointment and children's age at time of diagnosis, $r = .84, p < .001$.

Table 9

Professionals Consulted for ASD Diagnoses by Early vs. Later Diagnoses Groups

	Total (<i>N</i> = 28)		Early Dx Group (<i>n</i> = 12)		Later Dx Group (<i>n</i> = 28)	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Profession of Diagnosing Clinician						
Psychologist	18	62.1	7	58.3	11	64.7
Paediatrician	6	20.7	2	16.7	4	23.5
Psychiatrist	3	10.3	1	8.3	2	11.8
Family Physician	1	3.4	1	8.3		
Work Location of Dx Clinician						
Private Practice	6	20.7	1	8.3	5	29.4
Private Clinic	2	6.9	2	16.7		
Hospital clinic/office	3	10.3	2	16.7	1	5.9
Child Agency	17	58.6	6	50.0	11	64.7

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group $>$ 30 months.

Table 10

Inter-correlations Between Continuous Variables for All Participants

	1	2	3	4	5
1. Age at initial concern					
2. Delay in help-seeking	.08				
3. Age at initial appointment	.85***	.56			
4. Age at diagnosis	.67***	.54	.84***		
5. Household income before diagnosis	-.02	-.01	-.35	.05	

*** $p < .001$

Table 11

Inter-correlations Between Continuous Variables for Early Dx Group

	1	2	3	4	5
1. Age at initial concern					
2. Delay in help-seeking	-.69*				
3. Age at initial appointment	.40	.23			
4. Age at diagnosis	.35	.11	.44		
5. Household income before diagnosis	.41	-.24	.22	.50	

* $p < .05$

Table 12

Inter-correlations Between Continuous Variables for Later Dx Group

	1	2	3	4	5
1. Age at initial concern					
2. Delay in help-seeking	.29				
3. Age at initial appointment	.90***	.69**			
4. Age at diagnosis	.57*	.82***	.81***		
5. Household income before diagnosis	-.22	.15	-.10	-.06	

* $p < .05$; ** $p < .01$; *** $p < .001$

For the Early Diagnosis Group, Pearson correlations indicated a significant correlation between children's age at the time of initial concern about development and delay in help-seeking $r = -.69, p < .05$. These results indicate that for the children in the Early Diagnosis Group, the earlier parents were concerned about their children's development, the longer they waited to seek help for the concerns.

For the Later Diagnosis Group, there were significant correlations between children's age at the time of initial concern about development and children's age at the time of the initial appointment to address the concerns, $r = .90, p < .001$ and children's age at the time of the diagnosis, $r = .57, p < .05$. Significant correlations were also found between delay in help-seeking and children's age at the time of the initial appointment to address the concerns, $r = .69, p < .01$ and children's age at the time of the diagnosis, $r = -.82, p < .01$. A significant positive relationship between children's age at the initial appointment and children's age at time of diagnosis, $r = .81, p < .001$ was also found. These results indicate that for the children in the Later Diagnosis Group, the earlier there were concerns about the children's development, the earlier the children had an appointment to seek help for the concerns, and the earlier the children obtained diagnoses.

Data Screening

The following sections provide results of analyses completed to test assumptions related to dependent variables (i.e., age at initial concern, age at initial appointment, help-seeking delay, and age at first diagnosis).

Normality of distribution. Normality was first examined using visual inspection of histograms. Visual inspection of the histograms for the Early Diagnosis Group

revealed the variables help-seeking delay and age at first diagnosis showed slightly positively skewed distributions. Visual inspection of the histograms for the Later Diagnosis Group revealed the variables age at first concerns, age at first appointment, help-seeking delay, and age at first diagnosis showed slightly positively skewed distributions. Based on these findings, these variables appear to deviate from normal distribution.

The variables were further examined for normality using Q-Q plots generated with PASW Statistics, 18. A Q-Q chart plots the values expected from a normal distribution against the values actually observed in the data set. The expected values are on a straight diagonal line, whereas the observed values are plotted as individual points (Field, 2009). Data that are normally distributed would fall exactly along the line; however, each of the plots had an s-shape, deviating slightly from the line suggesting the data deviates from normal distribution.

To further test and confirm deviation from normality for these variables, both Kolmogorov-Smirnov and Shapiro-Wilk tests were conducted. These tests compare the values in the sample to a normally distributed set of values with the same mean and standard deviation. See Table 13 for a summary of the results for the sample. Table 14 summarizes the results for the two comparison groups.

The significance of the Kolmogorov-Smirnov and Shapiro-Wilk tests confirm deviation from normality in the distribution of the help-seeking delay variable and for age at diagnoses for both the Early Diagnosis Group and the Later Diagnosis Group. The age at initial concerns and age at initial appointment did not significantly deviate from normal distributions.

Table 13

Tests to Determine Normality of Continuous Variables

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	<i>df</i>	<i>p</i>	Statistic	<i>df</i>	<i>p</i>
Age at First Concerns	.164	28	.052	.961	28	.366
Help-seeking Delay	.216	28	.002**	.814	28	.000***
Age at First Appointment	.159	28	.069	.917	28	.030*
Age at Diagnosis	.138	28	.187	.920	28	.035

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 14

Tests to Determine Normality for Continuous Variables by Groups

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	<i>df</i>	<i>p</i>	Statistic	<i>df</i>	<i>p</i>
Age at first concerns						
Early Dx Group	.141	11	.200	.946	11	.588
Later Dx Group	.175	17	.172	.945	17	.377
Help-seeking delay						
Early Dx Group	.329	11	.002**	.692	11	.000***
Later Dx Group	.199	17	.073	.863	17	.017*
Age at first appointment						
Early Dx Group	.188	11	.200	.898	11	.174
Later Dx Group	.108	17	.200	.971	17	.832
Age at first diagnosis						
Early Dx Group	.448	11	.000***	.572	11	.000***
Later Dx Group	.456	17	.000***	.571	17	.000***

Note. Dx = diagnosis. Early Dx Group \leq 30 months; Later Dx Group $>$ 30 months.

* $p < .05$; ** $p < .01$; *** $p < .001$

Homogeneity of variances and outcome variable. A Levine's test was conducted to test the hypothesis that group variances were equal (i.e., the differences in the variables is zero) for the variables age at initial concerns, help-seeking delay, age at first appointment, and age at first diagnosis (see Table 15)

The Levine's test was not significant for the variables age at first concerns and help-seeking delay, indicating that the variances are the same. The Levine's test was significant for the variable age at initial appointment and age at diagnosis, indicating heterogeneity of group variances.

Power Analyses and Effect Sizes

A power analysis was conducted to examine the strength of the current study. Using the *G*Power 3.1.2* software program (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007), it was determined that the present sample size would detect a medium effect of $d = 0.5$ with .25 power for comparison of group means and detect a large effect of $w = 0.5$ with .52 power for comparison of categorical variables. Cohen (1992) suggests one should aim for power of .80 to provide an 80% chance of detecting an effect if one exists. The size of the present sample combined with uneven cell sizes (i.e., 12 earlier diagnoses versus 17 later diagnoses), compromised power for this research. Increasing the sample size and striving for equal cell sizes would reduce the possibility of Type I error.

Main Research Hypotheses

Results related to the specific research hypotheses outlined in the current study are described in the following sections. Each of the hypotheses will be analysed and presented separately.

Table 15

Levine's Test of Homogeneity of Variances for Four Variables

	<i>F</i>	<i>df</i>	<i>p</i>
Age at Initial Concerns	1.67	(27)	.208
Help-seeking Delay	0.48	(26)	.510
Age at Initial Appointment	10.03	(27)	.004**
Age at Diagnosis	14.81	(27)	.001

* $p < .05$; ** $p < .01$

Hypothesis I: Demographic variables.

1a: Mothers' level of education. It was predicted that higher levels of mothers' education would be associated with earlier diagnoses (e.g., Goin-Kochel et al., 2007). Chi-square analyses were performed to examine the association between mothers' education and age at diagnoses. As this hypothesis is based on research pertaining to mothers, all father participants were removed from the analysis (4 cases), reducing the sample size to 24 participants. The levels of education were collapsed into two categories because of the small sample size. The levels "high school or less" and "some college/university" were collapsed to create the category "less than college/university degree" and the levels "college/university degree" and "post-graduate" were collapsed to create the category "college/university degree or greater" resulting in a 2 X 2 contingency table. Chi-square analyses were performed and the resulting table examined to ensure that the assumption that the count in each cell is equal to or greater than the expected frequencies was met. As a general rule, the expected frequencies in each cell should be greater than 5 (Field, 2009). When using Fisher's exact test, cell numbers can be smaller, but should not be less than the expected frequency (Field, 2009). This assumption was violated as two cells had expected frequencies of less than expected and one cell had an actual cell count of zero (i.e., all mothers in the Early Diagnosis Group had a college or university degree or post-graduate degree) (see Table 16). Although there was a significant association between mothers' level of education and the age their children were diagnosed with ASD $\chi^2 (1) = 4.51, p < .05 (p = .047, Fisher's exact test)$ these results should be interpreted with caution because of the violation of the assumption of all cells having counts equal to, or greater than the expected frequency.

Table 16

Frequency Data for χ^2 Analyses of Maternal Level for Education

Group		Less than College/ University Degree	College/University Degree or Greater
		Early Dx ($n = 10$)	Actual Count
	Expected Count	2.1	7.9
Later Dx ($n = 14$)	Actual Count	5.0	9.0
	Expected Count	2.9	11.1

Ib: Family income at time of diagnosis. It was predicted that higher levels of income would be associated with earlier diagnoses and that families of children diagnosed with an ASD at or before 30 months would have had a higher family income at the time of diagnoses compared to other families in Ontario at that time (e.g., Goin-Kochel et al., 2007). Chi-square analyses were performed to examine the association between family income and age at diagnoses. As the sample size was small, the levels of income were collapsed into two categories. The levels “under \$25,000” and “\$25,000 to \$49,999” were collapsed to create the category “under \$50,000” and the levels “\$50,000 to \$74,999” and “over \$74,999” were collapsed to create the category “\$50,000 and over” resulting in a 2 X 2 contingency table. Chi-square analyses were performed and the resulting table examined to ensure that the assumption that the count in each cell is equal to or greater than the expected frequencies was met. This assumption was violated in one cell (see Table 17). There was a non-significant association between level of income and the age their children were diagnosed with ASD $\chi^2 (1) = 4.2, p >.05, (p = .033, Fisher's exact test; odds ratio = 0.11)$.

To assess the prediction that families of children diagnosed with ASD at or before 30 months would have had a higher income at the time of diagnoses compared to other families in Ontario at that time, the median income of participants with children diagnosed with ASD at or before 30 months of age was compared with the median income of all families in Ontario as reported by Statistics Canada for the year 2007. The hypothesis was not supported as participants of children diagnosed with ASD at or before 30 months of age reported income ($Mdn = \$62,499.50$) lower than all families in Ontario ($Mdn = \$69,190.00$) in 2007 (Statistics Canada).

Table 17

Frequency Data for χ^2 Analyses for Family Income

Group		Less than \$50,000	\$50,000 or greater
Early Dx ($n = 10$)	Actual Count	1.0	9.0
	Expected Count	3.3	6.7
Later Dx ($n = 14$)	Actual Count	7.0	7.0
	Expected Count	4.7	9.3

Exploratory. Family income of participants with children diagnosed with ASD at or before 30 months was compared to that of participants with children diagnosed later than 2 ½ years. The assumption of normality was violated for the Early Diagnosis Group, $W(10) = .837, p < .05$ and the Later Diagnosis Group, $W(14) = .821, p < .01$, indicating participants did not represent the normal population. The assumption of the homogeneity of variance was met, $F(1, 22) = .143, p < .05$. On average, parents of children diagnosed with ASD at or before 30 months had greater family income ($M = \$57,499.60; SE = 5,652.02$) than parents of children diagnosed later than 30 months of age ($M = \$57,142.50; SE = 4,852.68$). This difference was not significant, $t(22) = .048, p = > .05, r = .01$.

Hypotheses II: Initial concerns.

2a: Age of child at time of initial concerns. It was predicted that the age of children at the time of parents' initial concerns about their children's development would be associated with the age of their children at ASD diagnoses such that the earlier the initial concerns, the earlier the children would obtain diagnoses. An independent-samples *t*-test was conducted to examine the relationship between age at initial concern and age at diagnosis. There was a significant difference in means between children diagnosed with ASD at or before 30 months of age ($M = 15.92, SE = 1.84$) and children diagnosed with ASD later than 30 months of age ($M = 24.65, SE = 2.09$), $t(27) = -2.97, p < .01, r = .50$. On average, the younger children were at the time of their parents' initial concerns about their development, the younger children were when they were given diagnoses of ASD.

2b: Age of child at time of initial appointment about concerns. It was predicted that following parent's initial concerns about their children's development, parents of

children diagnosed with ASD at or before 30 months of age would have sought professional help for their children sooner compared to parents with children diagnosed with ASD later than 30 months of age (e.g., De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Siklos & Kerns, 2007). The age of children at the time of initial concern was subtracted from the age of children at the time of the first help-seeking appointment. This identified the time elapsed, in months, from initial concerns about the children's development to the initial appointment to get help for the concerns; this variable was labelled help-seeking delay. The help-seeking delay variable was examined for normality and homogeneity of variance. The assumption of normality was violated for the Early Diagnosis Group, $W(11) = .70, p < .001$ and the Later Diagnosis Group, $W(17) = .86, p < .05$. The assumption of the homogeneity of variance was met, $F(1, 26) = .05, p > .05$. An independent-sample *t*-test was conducted and no significant differences in help-seeking delay between parents of children diagnosed with ASD at or before 30 months ($M = 3.36, SE = 1.60$) and parents of children diagnosed with ASD later than 30 months of age ($M = 5.18, SE = 1.27$) was found, $t(26) = -.89, p > .05, r = .2$

Hypotheses III: Clinician variables.

3a: Profession of initial clinician. It was predicted that the majority of parents of children with an ASD would first seek help from their family physician or paediatrician rather than other professionals (e.g., Howlin & Moore, 1997; Osborne & Reed, 2008). As predicted, the majority of parents (68.9%) reported first seeking help from a physician, paediatrician, or neurologist rather than other professionals. Parents also reported first consulting speech and language pathologists (24.1%) and early childhood educators (3.4%).

Exploratory. Chi-square analyses were performed to examine the association between the initial professional consulted and age at diagnoses. As the sample size was small, the levels of initial professional were collapsed into two categories. “Family doctor,” “paediatrician,” and “neurologists” were collapsed to create one category, and “speech and language pathologists” and “early childhood educators” were collapsed to create the category “other professionals” resulting in a 2 X 2 contingency table. Chi-square analyses were performed and the resulting table examined to ensure that the assumption that the count in each cell is equal to or greater than the expected frequencies was met. This assumption was violated in two cells (see Table 18). There was a non-significant association between the initial professional consulted and the age children were diagnosed with ASD $\chi^2 (1) = .231, p > .05, (p = .231, Fisher's exact test; odds ratio = 3.1)$.

3b: Gender of initial clinician. It was predicted that the initial clinician consulted by parents of children with ASD diagnosed at or before 30 months was more likely to have been a woman compared to the initial clinician consulted by parents of children diagnosed with ASD later than 30 months of age. This hypothesis is based on research demonstrating gender differences in screening behaviour (e.g., Sices et al., 2003). Chi-square analyses were performed to examine the association between earlier diagnosis and the gender of the initial clinician consulted. Chi-square analyses were performed and the resulting contingency table examined to ensure that the assumption that the count in each cell is equal to or greater than the expected frequencies was met. This assumption was violated in one cell (see Table 19). There was a non-significant association between

Table 18

Frequency Data for χ^2 Analyses for Initial Professional Consulted

Group		Physician or Paediatrician	Other Professional
Early Dx ($n = 12$)	Actual Count	5.0	7.0
	Expected Count	3.4	8.6
Later Dx ($n = 16$)	Actual Count	3.0	13.0
	Expected Count	4.6	11.4

Table 19

Frequency Data for χ^2 Analyses for Gender of Initial Professional

Group		Woman	Man
Early Dx ($n = 12$)	Actual Count	4.0	8.0
	Expected Count	5.3	6.7
Later Dx ($n = 17$)	Actual Count	8.0	7.0
	Expected Count	6.7	8.3

gender of initial clinician and the age their children were diagnosed with ASD $\chi^2(1) = 1.08, p > .05, (p = .259, \text{Fisher's exact test}, \text{odds ratio} = .44)$.

3c: Number of professionals consulted. It was predicted that the number of professionals parents sought to get diagnoses of ASD for their children would be associated with earlier diagnoses, such that the fewer professionals sought, the earlier the diagnoses. An independent-samples *t*-test was conducted to examine the relationship between the number of professionals consulted and age at diagnosis. The assumption of normality was met for both the Early Diagnosis Group, $W(12) = .87, p > .05$ and the Later Diagnosis Group, $W(17) = .931, p > .05$ and the assumption of the homogeneity of variance was also met, $F(1, 26) = .001, p > .05$. On average, children diagnosed with ASD at or before 30 months of age were seen by fewer professionals ($M = 3.75, SE = 4.11$) compared to children diagnosed with ASD later than 30 months of age ($M = 4.29, SE = .351$). This difference was not significant, $t(27) = -1.00, p > .05$, although it represents a large-sized effect $r = .52$, accounting for about 25% of the variance.

It was predicted that parents of children with an ASD diagnosed at or before 30 months would have sought fewer than four professionals compared to parents with children diagnosed with ASD later than 30 months of age (e.g., Mandel et al., 2005). Chi-square analyses were performed to examine the association between the number of professionals consulted and age at diagnoses. The resulting table was examined to ensure that the assumption that the count in each cell is equal to or greater than the expected frequencies was met. This assumption was violated in one cell (see Table 20). There was a non-significant association between the number of professionals consulted and the age

Table 20

Frequency Data for χ^2 Analyses for Number of Professionals Consulted

Group		< 4 Professionals	> 4 Professionals
Early Dx ($n = 12$)	Actual Count	7.0	5.0
	Expected Count	5.4	6.6
Later Dx ($n = 17$)	Actual Count	6.0	11.0
	Expected Count	7.6	9.4

children were diagnosed, $\chi^2 (1) = 1.51, p > .05, (p = .20, Fisher's exact test, odds ratio = .11)$.

Hypotheses IV: Parental perceptions and expectations

For the following hypotheses, parents were asked to think back to when they first became concerned about their children's development and rate the following:

4a: Perception of the possibility of their children having a developmental disorder (threat).

4b: Perception of the seriousness of their children having a developmental disorder to their future outcome (e.g., school performance, making friends).

Independent-samples *t*-tests were conducted to examine differences between the Early Diagnosis Group and the Later Diagnosis Group. On average, both groups reported perceiving there was "some" threat of the possibility of their children having a developmental disorder and "some" seriousness to their children's future outcome. The differences between groups were non-significant (see Table 21)

For the following hypotheses, parents were asked to think back to when they first became concerned about their children's development and rate the following:

4c: Perception of their knowledge of child development.

4d: Perception of their knowledge about ASD.

Independent-samples *t*-tests were conducted to examine differences between the Early Diagnosis Group and the Later Diagnosis Group. On average, both groups reported having "some" knowledge of child development and "little" knowledge of ASD. The differences between groups were non-significant (see Table 22).

Table 21

Differences Between Early vs. Later Diagnoses Groups for Perception of Threat Expectations

Question	Early Dx Group (<i>n</i> = 12)		Later Dx Group (<i>n</i> = 17)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
The possibility of your child having a developmental disorder ^a	3.25	1.21	3.18	1.55
The threat of your child's condition to future developmental outcomes ^b	3.75	1.22	3.71	1.49

Note: 1 = none; 2 = little; 3 = some; 4 = moderate; 5 = very

^a $t(27) = 137, p > 05, r = .03, ns$

^b $t(27) = .084, p > 05, r = .005, ns$

Table 22

Differences Between Early vs. Later Diagnoses Groups for Perception of Knowledge

Question	Early Dx Group (n = 12)		Later Dx Group (n = 17)	
	M	SD	M	SD
Knowledge about child development	3.92	0.90	3.35	0.93
Knowledge about ASD	2.42	1.24	2.29	1.16

Note: 1 = none; 2 = little; 3 = some; 4 = moderate; 5 = very

^a $t(27) = 1.627, p > .05, r = .09, ns$

^b $t(27) = .272, p > .05, r = .02, ns$

For the following hypotheses, parents were asked to think back to when they first became concerned about their children's development and rate the following:

4e: Perception of ability to decide what help their children need.

4f: Perception of ability to find the help their children need.

4g: Perception of ability to get professionals to take action.

Independent-samples *t*-tests were conducted to examine differences between the Early Diagnosis Group and the Later Diagnosis Group. On average, both groups perceived themselves as having “moderate” ability to decide what help their children needed and to find help for their children. On average, the Early Diagnosis Group perceived themselves as having “some” ability to get professionals to take action and the Later Diagnosis Group perceived themselves as having “moderate” ability to get professionals to take action. The differences between groups were non-significant (see Table 23).

4h: Perception of general self-efficacy (GSE). Parents were asked to think back to when they initially became concerned about their children's development and rate their perception of their general self-efficacy using the general self-efficacy subscale (GSE) of the Self-Efficacy Scale (SGSE; Sherer et al., 1982). It was predicted that parents of children diagnosed with ASD at or before 30 months would report higher general self-efficacy compared to parents of children diagnosed with ASD later than 30 months of age. An independent-samples *t*-test was conducted to examine differences between the Early Diagnosis Group and the Later Diagnosis Group. This hypothesis was not supported as, on average, parents of children diagnosed with ASD later than 30 months of age reported a greater perception of their general self-efficacy ($M = 66.06, SE = 2.22$)

Table 23

Differences Between Early vs. Later Diagnoses Groups for Perception of Ability

Question	Early Dx Group (n = 11)		Later Dx Group (n = 17)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Ability to decide what help their children need ^a	4.64	0.67	4.53	0.62
Ability to find help their children need ^b	4.18	0.87	4.24	1.03
Ability to get professionals to take action ^c	3.82	1.25	4.24	1.20

Note: 1 = none; 2 = little; 3 = some; 4 = moderate; 5 = very

^a $t(26) = .429, p > .05, r = .03, ns$

^b $t(26) = -.142, p > .05, r = .03, ns$

^c $t(26) = -.884, p > .05, r = .03, ns$

compared to parents of children diagnosed with ASD at or before 30 months ($M = 60.91$, $SE = 4.04$) although this difference was not significant, $t(27) = .237$, $p > .05$, $r = .23$.

In a construct validation study of the Self-Efficacy Scale, Sherer and Adams (1983) reported a mean score of 64.31 on the General Self-Efficacy Subscale. On average, parents of children diagnosed with ASD at or before 30 months of age scored 60.91, below the reported mean score of 64.31. On average, parents of children diagnosed with ASD later than 30 months of age scored 66.06, above the reported mean of 64.31.

Exploratory. The Health Beliefs Model proposes that cues-to-action may trigger the decision-making process (i.e., prompt parents to be concerned or to seek help). Parents reported being cued to take action by a variety of cues at the time of their initial concerns about their children's development. Cues in the environment prompting parents to be concerned about their children's development included flyers, media programs on child development or ASD, workshops, and contact with someone who had a child with a developmental disability or ASD (see Table 24). Seven parents reported seeing flyers on child development that cued their concerns about their children's development. They reported seeing flyers at Ontario Early Years Centres ($n = 3$), Speech and Language clinics ($n = 2$), a day care centre, a family physician's office and one parent reported receiving a flyer in the mail from a district health unit.

Thematic Analysis of In-depth Questionnaires

Each of the 21 interviews was recorded, transcribed, and checked for accuracy. The transcripts were then read in their entirety several times to gain an understanding of the participants' experiences (Attride-Stirling, 2001; Braun & Clarke, 2006). Following this, hierarchical structures were created with the question asked as the category at the

Table 24

Frequency Data for Cues in Environment and Media that Prompted Parents to Take

Action

Cue	<i>N</i>	%
Other	13	48.8
Poster or flyer on child development	8	27.6
Knew someone with a child with an Autism Spectrum Disorder	6	20.7
Knew someone with a child with a Developmental Disability	5	17.2
Knew someone who was concerned about their child's development	3	10.3
Television ad or program on child development	2	6.7
Radio ad or program on child development	2	6.7
Workshop or presentation on Autism	2	6.7
Television ad or program on Autism	1	3.4
Video ad or program/promotion on Autism	1	3.4

N = 29

top, then moving to more specific categories below (i.e., emerging themes). The next step was to begin the thematic analysis of each question by first grouping similar responses together by emergent themes and sub-themes. The following are the results of the thematic analysis presented by research questions and using participants' quotes to support the development of the thematic themes. Pauses in samples of parents' responses are identified by ellipsis (...).

What do you think helped you the most (to receive diagnoses earlier)? This question was concerned with the factors parents perceived as helping them the *most* in obtaining diagnoses of ASD for their children.

Parent persistence. Almost half of the parents reported their own persistence as being the main factor that helped them obtain diagnoses for their children. Parents reported having to convince physicians that their concerns were valid, advocate for their children's right to be assessed, educate themselves on ways to help their children, and for some, pay to find answers to their concerns.

Research....and... I would have to go with persistence. (Mother P)

Probably initiative on our part and being concerned in the first place, and then following all of the leads that we managed to get a hold of... (Mother U)

Almost half of the parents indicated that a specific program or professional was the most important factor in helping them obtain diagnoses earlier.

It was actually one of (my child's name) um, first speech therapists that assessed him that mentioned (hospital in U.S.) to us, so if it wasn't for her I never would have known about the (hospital in U.S.), so I think it was her giving us this information and saying do whatever you want with it. (Mother F)

Definitely I would attribute it to, um, (name of social worker) she is the coordinator at (mental health centre for children 0 to 6 year), okay, um, she kind of, like, um, she's a social worker that had the ins and outs and understanding. (Mother D)

Physicians. Three parents indicated that their family physicians or paediatricians were the most important factor in obtaining earlier diagnoses because of they brought symptoms and characteristics of ASD to parents' attention and took time to talk to parents.

Their willingness to talk, because this is not like...ah you have high blood pressure, this is a psychological issue...so the willingness to explain information from the people involved, and that's my experience, just the willingness of the docs to explain and empower the parents with information, that was one of the big things. (Father D)

I just went to my family doctor for a normal check-up and he just asked me is she talking and I said no, not really, she doesn't really have to because I give her everything and ... when he told me that she wasn't she should be saying a few words...that she was saying at 9 months, but she lost them...that he wanted me to go to a paediatric doctor. (Mother T)

Another parent with a child with ASD. One parent indicated that it was another parent with a child with ASD that was the most important factor.

Talking to a family member who has a child that has autism... that really brought things around for me, into going and getting that diagnosis and, um, and to, to going, just going ahead as quickly as possible to get a diagnosis, I would say that would be the, the main thing that stands out...um...yeah. (Mother H)

What do you think helped you the least? Parents were asked to indicate what they perceived as helping them the *least* in obtaining diagnoses for their children. Some parents reported that physicians had told them that nothing was wrong and failed to take their concerns seriously. Other parents reported that family and friends were the least helpful. Finally, parents reported that waiting and wait lists were the least helpful in obtaining diagnoses earlier.

Physicians. Several parents indicated the family physicians or paediatricians were the least helpful in helping them obtain diagnoses.

Yeah the family doctor for sure ...he uh because I mean if, if I didn't you know, push it, he would have just uh and if I didn't you know sort of have my sister-in-law you know, saying to me you know, push for this, push for this you know, I might have just been like, oh okay he says its fine there's nothing wrong and you know, I might not have pursued it so cause you know, he was willing to just explain it away, that they weren't issues ... (Mother A)

Yeah, my doctor saying that there's nothing wrong, that it's a typical boy behaviour. Um...and me asking her other questions about 'oh, could it be this, could it be this' and she still said no...um, and even when we had received the diagnosis she's like 'oh I didn't see any of that'...in him so. That's, that's very frustrating to me, is, if they're trying to do the screening earlier and they can't even realize it, like, I went into her before I called the Speech and Language clinic about his lack of speech. She said 'oh it's just a boy thing, he'll grow out of it, he'll get his speech' but he didn't, two months later and that's what made me call the Speech and Language clinic program because I knew there was something with the speech... (Mother G)

Family and friends. Although acknowledging that family and friends may have meant well, some parents indicated that they were the least helpful in helping parents obtain diagnoses.

Family and... families and friends...um...just, you know, giving me their two cents worth...you know... feeling I was crazy, it didn't help... um... you know it would make me second guess sometimes that maybe I was over-reacting...but...like I said, my persistence paid off, I thought, I always told myself, you know what...if it's not autism...even then...you know umm... I kept thinking that would be, I think that was the things I found the hardest to deal with... was just family and friends...putting up roadblocks and stuff. (Mother P)

Oh, well, some people were saying 'oh, it's normal, children will talk' you heard it all the time, like, my friends, my colleagues, my relatives were saying like 'oh no, no she'll be okay, it's normal, some kids don't talk 'til they're five years old' or things like that, right, and then just wait it will get, go, like, even at the office they tell me, like, you know, 'just wait, she'll, she'll be okay, she's, she's developing' or if you see my (child's name) she looks normal except the people sometimes, but that's the one, that, that didn't really help, like, if I had probably listened to them, I would not be where I am right now. (Mother B)

Wait time. Three parents indicated that wait lists and waiting for appointments was the least helpful in helping them obtain diagnoses.

Waiting. The waiting is the worst. The not knowing...and then knowing, but can't say to us ...because it wasn't diagnosed, it had to be diagnosed by a doctor.
(Mother J)

The least....ummmm...the wait time....for the referral. (Mother, Interview 17)

Lack of knowledge. Parents indicated that a lack of knowledge or awareness about ASD was the least helpful in helping them obtain diagnoses.

The least?...I'd hate to say this but Healthy Babies, I really like Healthy Baby's because...I was involved with them with my first child, but...with my second child, and ah, my third child, they, they, know nothing about it (autism), they basically knew nothing about it. I kept on asking them for this and this and this, where as in the other place, I always got my answers that I was looking for.
(Mother N)

It took about 2 years to find out exactly what was wrong with my son ...from the onset of the problem...and it was just like....I didn't have the information...like if the doctor would have said like, there is the (name of agency), there is, and he (doctor) should know, like he should of known about (name of agency), like, it is right next door. You know if I would of, you know I only found out about (name of centre that diagnosed child) because I called Autism Ontario to get umm... parenting classes because I was going crazy at home... (Mother W)

What do you think were the main factors that helped you to get an ASD

diagnosis earlier for your child? This question was concerned with the factors in general that parents perceived as helping them get a diagnosis of ASD for their children. Most parents reported several factors that contributed to their success.

Physicians. Some parents indicated that their family physicians or paediatricians were helpful in that they brought developmental concerns to parents' attention or provided them with support and information.

Um, the other main thing was that we had an amazing doctor who was very proactive... (Mother F)

Certainly visiting my family doctor when he suggested that I would have him...ah...have autism ruled out. I don't think if it wasn't for that I probably would have...the process perhaps would have been much more delayed. (Mother Q)

Other parents indicated that their physicians or paediatricians were not supportive or lacked the knowledge to diagnose their children.

I couldn't go and I gave him (her husband) the list of everything to tell the doctor why we wanted a referral and uh... he told my husband he didn't think we needed it and he just kind of sloughed off, like, the thing to him was all the sensory issues and he ...I forget exactly what he said but I know for each issue that my husband told him that I had written down, the doctor just explained it away like 'oh some kids are like that' or whatever right, and um... so anyways my husband came back home with no referral for the paediatrician. (Mother A)

I don't think that medical professionals, um, not all of them but a lot of them, don't have the right training to recognize this condition in, in young children. (Mother K)

Family members and friends. Some parents reported that family members and friends played a role in helping to obtain diagnoses, either by drawing attention to developmental concerns or encouraging parents to consult with physicians.

I talked to my sister-in-law..... because she has a history working with children experiencing children's mental health like... she's worked with them for a long time and she knows um, you know, typical development and all that kind of stuff so when we spoke to her, like I said, she actually knew he had autism but she did not tell me um and the reason why, she told me after, is because she, she didn't think we would believe it and she also figured that it would get caught once he started school and having said that she...when I told her all of my concerns she did encourage me to um you know go to the doctor and you know push for um you know a referral to a paediatrician. (Mother A)

My mother-in-law mentioned it to me...and... she....I think initially saw a...Speech and Language clinic flyer at one of the Ontario Early Years...that I think it was some sort of pie, or some kind of notification of... is your child not answering to his name, is he not verbalizing.... and all those kinds of things...so... those are the kinds of things that she sort of mentioned to me after she had brought him and my other child to the Ontario Early Years centre. (Mother R)

Cues in the environment. Parents indicated that cues in their environment such as seeing a poster or listening to a radio program helped them obtain diagnoses.

There was a child development, um, program on through AM 800 is basically what it was, and there was a child development person on there and she just kind

of did a whole skit on what you should be looking for initially, so I, I heard that radio program and I, like... some bells kind of rang off. (Mother D)

Our doctor referred us to a local early communication program... called Speech and Language clinic, ...and they um...there was a big long waiting list for them but when we got to the ah...orientation for it there was a big poster ... for a study on early intervention for autism and our son seemed to fit all of those parameters... so we called them and basically it was luck that we got into that study, ...and that is what led to an earlier diagnosis than he otherwise would have received. (Mother U)

Staff from children's treatment agencies. Several parents reported that staff working for children's treatment agencies were a factor in obtaining diagnoses.

We were actually red flagged by somebody at um...an Ontario Early Years Centre...we were just there for, um our first time going there was for a tour and...they noticed his behaviour and red flagged us and...within a month we were, we were in um...an early intervention program. (Mother M)

Because (my child's name) was premature, they had someone from (Children's treatment agency)... they had an early intervention worker come out...each month...to check him for milestones. So, because they were coming out each month, they brought things to my attention that I think I would have not noticed otherwise. So the fact that someone was continually monitoring him because he was a preemie certainly helped us get the diagnosis. (Mother V)

Parents also indicated that becoming involved with speech and language programs was a factor leading to earlier diagnoses.

We called the (Speech and Language clinic) because of his lack of speech my husband thought that maybe it was just speech that was causing him to not want to socialize, because he didn't know how to communicate, but then, when we did the (Speech and Language clinic) they brought up other, like the red flags of the lack of eye contact, the odd behaviour with, uh, playing with toys, not playing with dolls or stuffed animals, um, and no imaginative play... (Mother G)

I didn't know about autism at all, um...but when I saw (speech pathologist) at the (Speech and Language clinic), she was the only one who gave me any idea about what could be going on...so... she said she thought it might be autism... (Mother W)

Over half of parents reported their own persistence in pursuing answers for their concerns was a factor in obtaining diagnoses earlier. As all of these parents indicated that

their persistence was the most helpful factor in obtaining diagnoses, their comments are not repeated here.

Is there anything else you would like to tell me about your experience obtaining a diagnosis for your child? Parents responded to this question by providing suggestions and advice to other parents about obtaining diagnoses for their children. Following parental instinct, being persistent, and not delaying were the predominate themes.

Instinct and intuition. Believing in and following maternal instinct and intuition was a common theme among parents.

If you feel it in your gut, go for it, and ask for help. (Mother G)

Yeah, yeah, I can't complain, you really just have to be optimistic and ah...yeah stick with your gut. (Mother L)

Be persistent, advocate. Several parents encouraged others to be persistent and advocate for their children.

If...one medical professional can't give you the information you want, don't hesitate to ask somebody else, you got to do what's best for your child. (Mother G)

Really push because a lot of time the family doctors will say they'll just grow out of it, it's a stage, but you really can't... if you really research it and say these are the symptoms and matching to me...and say 'what do you think?' What you think is very helpful and you can really be your own advocate for your own kid. (Mother M)

Don't delay. Parents encouraged others not to delay because of long wait lists and the importance of early identification.

Don't ignore what you think are symptoms....like don't put it off ... (Mother M)

The thing I'd like to say to other parents is that um, you want to diagnose your kids as early as possible because if you don't you...um...you'll find out if you don't. It took me three years to get my son into a daycare. (Mother N)

Other Themes

In addition to the themes that emerged in response to the questions, another theme with sub-themes emerged during the reading and re-reading of the transcripts. Parents indicated that they experienced a number of reactions to learning of their children's diagnoses, both negative and positive.

Negative experiences.

Shock and denial. Some parents reported feeling shock and denial at the time of learning of their children's diagnoses.

It didn't occur to me it was autism...so I had no reason not to... ahh worry...um...I know that once we started receiving services it did take a while ummm...to like... make my husband all right with the diagnosis, because he was... in denial. (Mother Q)

Initially of course I was in denial like everyone else and didn't want to hear it and didn't think that it could possibly happen to me. (Mother V)

Positive experiences.

Parents reported positive experiences in response to learning of their children's diagnoses as well as negative experiences. Some parents reported experiencing a sense of relief on learning of the diagnoses, of being glad or grateful, and a sense of clarity and of benefiting from the knowledge.

Relief. Parents reported feeling relief because they had validation for their initial concerns and they had a path to follow.

I still remember the day it, it was our son's second birthday that we went over there for our final meeting with the, the team and it was just, it was a relief at the same time, um, yeah, it was just, it was a great relief, because at least we knew now what we were dealing. (Mother F)

I felt relieved once I had it, I felt that I knew I'd been on the right track and that I was observing...with my eyes and ears...and I had done my research. (Mother P)

Clarity and benefits. Some parents reported feeling a sense of clarity and that their diagnoses would help them access community resources.

Ummm, yeah, and just, once you know it's...its almost liberating... you almost...you finally have a path to follow or at least ...you know a little bit more about what you are up against. (Mother V)

We had a list of things that that we needed to do and I took that list and I started checking them off right away, this is what we need to do, we did this, we did this, and then the final recommendation was the ABA therapy. So it, it's, you know, it was a short process for us. (Mother F)

Glad or grateful. Parents reported feeling glad, or grateful that they had followed through with their concerns.

I'm glad that I did it, I'm glad that I followed through on my...you know...mothers' intuition...as they say...um...that I pushed for it... (Mother P)

I can't believe that it happened, but it's, um, you know, we're glad, we're glad that we did it (Mother 6)

Summary of Results

Through the retelling of their experiences as they sought diagnoses for their children, parents described a number of factors that helped or deterred them in obtaining earlier diagnoses. While their experiences are varied and individual, there were several central themes and sub-themes that emerged. Table 25 provides the themes and sub-themes.

Table 25

Primary Themes and Sub-Themes

Research Question	Primary Themes & Sub-Themes
What helped the most?	<ul style="list-style-type: none"> Parent persistence Other programs and professionals Physicians
What helped the least?	<ul style="list-style-type: none"> Physicians Family and friends Wait-time Lack of knowledge
Main Factors that helped get diagnosis earlier?	<ul style="list-style-type: none"> Physicians <ul style="list-style-type: none"> Helpful Not-helpful Staff from child treatment agencies Family and friends Cues in environment/media Parent persistence
Anything else about your experience?	<ul style="list-style-type: none"> Advice to other parents <ul style="list-style-type: none"> Instinct and intuition Be persistent/advocate Don't delay Feelings at diagnosis <ul style="list-style-type: none"> Negative <ul style="list-style-type: none"> Shock and denial Positive <ul style="list-style-type: none"> Relief Clarity and benefits Glad or grateful

Chapter IV

Discussion

The present study investigated factors that influence parents toward earlier diagnoses of ASD for their children. Utilizing a Canadian sample from the province of Ontario, results are similar to that of other studies conducted in other areas of the world (e.g., Baghdadli et al., 2003, France; Chawarska et al., 2007, U.S.; De Giacomo & Fombonne, 1998, U. K.; Goin-Kochel et al., 2006, U. S.; Howlin & Moore, 1997, U. K.; Mandel et al, 2005, Pennsylvania, U. S.; Osborne & Reed, 2008, U. K.; Sices et al., 2004, U. S.; Siklos & Kerns, 2007, British Columbia, Canada; Young et al., 2003, Australia).

Although past research suggests the average age of diagnosis is decreasing over time, it is still relatively high given the importance of early intervention. Parents are often the first to recognize the early symptoms of ASD (e.g., language delay, deficits in social skill, atypical behaviours, and delays in developmental milestones). Subsequently, parents seek professional help for their concerns about their children's development.

The present study was concerned with identifying demographic variables (e.g., maternal education, family income), clinician variables (e.g., profession and gender of referring and diagnosing clinicians), and parent variables (e.g., beliefs and perceptions about their children's atypical development and delays, beliefs and perceptions about barriers and benefits) that influence parents' pursuit of early diagnoses of ASD for their children.

Although not all hypotheses were supported statistically, possibly because of the small sample size and low power as a result of uneven cell sizes, there are reasons to suggest significant results may be found in a repeated process with a larger sample size.

Thus, additional research is needed to investigate the influence of demographic and

parental factors on the age children receive diagnoses of ASD in a larger, more diverse sample.

Initial Concern

In 69% of cases, parents were the first to become concerned about their children's development and in a further 10.3% of cases, grandmothers were the first to become concerned, indicating that almost 80% of children were identified as having developmental concerns by parents or extended family members. In only 6.9 % of cases were physicians the first to become concerned. As in the majority of cases, delays or concerns in development were first noticed by parents or extended family, it is important that parents have access to information on not only typical developmental milestones, but also on symptoms and characteristics of ASD. It is interesting to note that in 83.3% of cases of children diagnosed at or before 30 months of age, parents or grandmothers were the first to become concerned, with the remaining 16.7% of cases being first identified by speech and language pathologists or early childhood educators. Thus, it is also important that professionals such as speech and language pathologists and early childhood educators also have information about the symptoms and characteristics of ASD. Further, results of this research suggest that physicians are not identifying early symptoms and characteristics of ASD at well-baby check-ups. Some parents who participated in this study expressed concerns about developmental screening during check-ups failing to identify symptoms and characteristics related to ASD. For example, one parent of a child diagnosed with ASD later than 30 months of age stated:

Our paediatrician, he tried, but, you know, a lot of the checklists and stuff that are designed to catch this didn't do it, they, the measures were not good you know, our doctors asked us questions that, in retrospect, should have caught her

developmental issues and didn't, so I really feel that a lot of parents are, you know, missing out because they are relying solely on that.

Areas of initial concern. The majority of parents had concerns in more than one area of their children's development. Similar to past research in this area, the majority of parents were concerned about language development (86.2%), behavioural issues (58.6%), and social skills (55%) (e.g., Baghdadli et al., 2003; Chawarska et al., 2007; De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Siklos & Kerns, 2007; Young et al., 2003).

Age at initial concern. On average, parents first became concerned about their children's development when children were 21.03 months of age; comparable to past research in this area (e.g. Baghdadli et al., 2003, De Giacomo & Fombonne, 1998; Howlin & Moore, 1997). Overall, 17.2% of parents reported becoming concerned by their children's first birthday, 75.9% by the second birthday, and 96.6 % by the third birthday; this is comparable to past research (e.g., De Giacomo & Fombonne, 1998; Siklos & Kerns, 2007).

It was predicted that the earlier parents had concerns about their children's development, the earlier the children would obtain diagnoses. Seventy-five percent of parents with children diagnosed with ASD at or before 30 months of age became concerned about their children's development before their children were 18 months of age compared to 35.4% of parents with children diagnosed with ASD later than 30 months of age. This difference was significant; the earlier parents became concerned about their children's development, the earlier the possibility of obtaining diagnoses. These results further emphasize the importance of parents and professionals who come in contact with very young children having access to and knowledge of information on both

typical developmental milestones and symptoms and characteristics of ASD. There is considerable evidence to support the feasibility of identifying children with ASD by the time they are 18 to 24 months of age (e.g., Brian et al., 2008; Matson et al., 2008; Pandey et al., 2008; Wetherby et al., 2008; Zwaigenbaum, 2010) if a concern about development is recognized and a referral is made to an experienced clinician for assessment of ASD.

Seeking Help from Professionals

Help-seeking delay. It was predicted that the sooner parents sought professional help for their concerns about their children's development, the earlier their children would be diagnosed with ASD. Although the difference was not significant, on average parents of children diagnosed with ASD at or before 30 months of age sought help from a professional within 3.36 months, compared to parents of children diagnosed with ASD later than 30 months of age who sought help within 5.18 months. Past research has found that, on average, parents report seeking help from a professional within 5 to 11 months (e.g., De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Siklos & Kerns, 2007; Young et al., 2003); comparable to the children in the present study diagnosed later than 30 months of age.

Initial clinician consulted. Parents reported taking a variety of actions at the time of their first concerns, including talking to friends, preschool or daycare staff, reading books, and researching on the internet. One parent reported:

We looked at some internet resources including the video glossary on Autism Speaks, which had a lot of good footage on typical versus ASD kids, and we knew that our child really fell into that ASD category; we thought 'oh gosh, we really think this is totally it.

Parents also reported contacting a variety of professionals, including family physicians, paediatricians, neurologists, audiologists, speech and language pathologists,

and early childhood educators at Ontario Early Years Centres. It was predicted that the majority of parents would first seek help from physicians or paediatricians rather than other professionals. As predicted, the majority of parents (68.9%) first sought help from physicians, neurologists, or paediatricians; this is comparable to past research (e.g., Howling & Moore, 1997; Osborne & Reed, 2008). No significant differences were found between the early and the later diagnoses groups in regard to whether they first sought help from their family physicians or paediatricians, or they first sought help from other professionals.

It is interesting to note that 33.3% of the early diagnoses group reported first seeking professional help from a speech and language pathologist, whereas only 17.7% of the later diagnoses group reported first seeking help from a speech and language pathologist. As language development was a concern for 86.2% of parents, it is logical to think that parents would seek help from a speech specialist. Fifty percent of the parents in the early diagnoses group reported that a speech and language pathologist referred them to the clinicians that provided diagnoses compared to 29.4% of parents in the later diagnoses group.

A further 17.6% of parents in the later diagnoses group were referred to the diagnosing clinician by an occupational therapist. Overall, 58.6 % of the sample was referred to the diagnosing clinician by speech and language pathologists or occupational therapists compared to 3.4% by family physicians and 31% by paediatricians. This suggests that speech and language pathologists and occupational therapists may be recognizing the symptoms and characteristics of ASD and referring parents for further

assessment resulting in earlier diagnoses, more often than physicians and paediatricians. Further research is needed to investigate this.

Past research suggests that paediatricians are more likely to make referrals for further assessment than are family physicians (e.g., Sices et al., 2004). Similar to past research, the present study found that overall; more children were referred for further assessment by paediatricians (31%) than by family physicians (3.4%).

It was predicted that more of the initial clinicians consulted by parents of children diagnosed with ASD at or before 30 months of age would be women. This hypothesis was based on past research that suggests that women professionals are more likely to provide more screening and referrals compared to men (e.g., Sices et al., 2003). This hypothesis was not supported. Twenty-five percent of the clinicians initially consulted by the Early Diagnoses group were women compared to 75% men. Results from the 2006 Canadian census indicate that in the province of Ontario, approximately 37% of physicians are women and 63% are men (Statistics Canada, 2006). Further, speech and language pathologists are predominantly women (93.5%) (Statistics Canada, 2006). Given this information, if women professionals are more likely to provide more screening and referrals compared to men as previous research suggests, one would expect parents of children diagnosed at or before 30 months of age to have initially consulted a higher percentage of women professionals than was found in the current study.

It was predicted that the number of professionals from whom parents consulted to get diagnoses of ASD for their children would be associated with earlier diagnoses, such that the fewer professionals consulted, the earlier parents would obtain diagnoses for their children. This hypothesis was not supported as there were no significant differences

between the groups in relation to the number of professionals consulted. On average, parents consulted 4.07 professionals; comparable to the results of a Canadian study conducted by Siklos and Kerns (2007) in which they found that on average, parents consulted 4.46 professionals. It is possible that parents were seeing more than one professional simultaneously, for example, speech and language pathologists, occupational therapists, and physiotherapists during the same time frame as they were seeking help from their physicians or paediatricians. As one parent of a child diagnosed at or before 30 months of age reported:

I would take him to their centre which involved um...views of him by a physiotherapist, an occupational therapist, and a speech pathologist... so because they were involved so early and... had the ability to monitor him and watch him... that's I think what did it.

Age at diagnosis. In the present study, the average age of children at the time of diagnoses was 36.03 months (range 20-61 months); this is younger than reported in previous research. The children's age at diagnosis ranged from 20 to 61 months, with the average age for the early diagnoses group being 25 months and the average age for the later diagnoses group being 43.82 months. In a sample of 1295 families from the U. K., Howlin and Moore (1997) found that on average, children were diagnosed at 6.11 years. In a sample of 969 caregivers of children with ASD from Pennsylvania, U. S., Mandel et al. (2005) found that, on average children with autistic disorder received diagnoses at 3.1 years, children with PDD-NOS at 3.9 years, and children with Asperger's Disorder at 7.2 years. In a Canadian sample, Siklos and Kerns, (2007) found that on average children were diagnosed at 5 years. It is possible that the average age at diagnoses for the present research is younger because participants were restricted to parents of children under the age of 6 ½ years of age with diagnoses of ASD. Further, the sample size was small and

nearly 50 % of the sample was represented by children 24 to 36 months of age at time of diagnoses. As part of the research procedure for this study, parents were asked to provide their children's diagnostic report. Seventeen diagnostic reports were received representing a 58.6% return rate. Of the reports received, four (23.5%) revealed errors in parent report on age of diagnosis (ranging from 2 to 14 months) and 1 (5.9%) revealed an error in parent report on the actual diagnostic label. Taking this into consideration, one could project that of the participants without returned diagnostic reports, 77% are likely to be accurate about their children's diagnosis.

The diagnosing clinician. The majority of the children in the present study were diagnosed by psychologists, followed by paediatricians, psychiatrists, and family physicians, although one child received a diagnosis of ASD from a family physician. It is possible that family physicians may not be as knowledgeable about the symptoms and characteristics of ASD. As one parent stated, "I don't think that medical professionals, um, not all of them but a lot of them, don't have the right training to recognize this condition in, in young children."

The majority of the diagnosing clinicians (58.6%) were associated with agencies providing services and interventions to families of young children, such as speech and language therapy. The reason for this could be related to Ontario's public health services. Parents may choose to seek help from government funded agencies because the intervention is covered by Ontario's provincial health services. As one parent stated, "I think because in Canada we're so trained as parents and as citizens to rely on our public system that we never think outside the box..." This could be an advantage in some cases as children could be red flagged by staff at these agencies as parents seek interventions

from speech and language pathologists, occupational therapists, and physiotherapists, thus moving the children toward earlier diagnoses. Alternatively, there are often long waitlists for services and this could delay diagnoses. As one parent reported when asked what helped the most in obtaining a diagnosis for her child:

I don't know, everything took forever to get there, poor kid, um, the uh, I guess just having (mental health centre for children 0 to 6 years) stand by us even though they took their sweet time getting, you know, appointments and all that other good stuff because they've so many children on the spectrum, we had to wait our turn.

The majority of the parents did not pay a fee for their children's diagnoses as only 16.7% of parents in the early diagnoses group and 11.8% of parents in the later diagnoses groups reported paying a fee for diagnoses obtained privately. One parent reported:

We were aware that psychologists could diagnose the disorder, whereas a lot of parents don't know that, and that we were in a financial position where we could privately obtain a diagnosis from a psychologist, um, we did proceed through the public system, but there was a 9 to 10 month wait to see a developmental paediatrician and we knew if we did that, then (child) would, her intervention would be delayed by at least that long and we just weren't willing to do that.

Diagnostic Variables Related to Early Diagnoses

Maternal education. It was predicted that higher levels of maternal education would be associated with earlier diagnoses based on past research suggesting that as maternal level of education increases, age at diagnoses decreases (e.g., Goin-Kochel et al., 2006). This hypothesis was supported although a certain amount of caution needs to be taken as the sample size was small. It is interesting to note that in this sample, all of the mothers of children diagnosed at or before 30 months of age had a college or university degree or higher, compared to 58.8% of mothers of children diagnosed later than 30 months of age. Parents with higher education appear to be over-represented in the current sample compared to the provincial average (Statistics Canada, 2006).

Family income. It was predicted that higher levels of family income would be associated with earlier diagnoses and that families of children diagnosed with ASD at or before 30 months of age would have had higher family income at the time of diagnoses compared to other families in Ontario. These hypotheses were not supported. In the present sample, there was no association between age of diagnoses and level of family income. This could be due to the small sample size. Families of children diagnosed with ASD at or before 30 months of age reported having lower family income compared to other families in Ontario at the time of diagnoses. A recent study based in the U. S. found that women with a child with ASD had made changes in their work lives to accommodate their child's autism (Baker & Drapela, 2010). Over half of the women were working fewer hours and three out of five women were not working outside the home because of their child's ASD (Baker & Drapela, 2010). Similarly, Montes and Halterman (2008) found that after controlling for maternal education, type of family, parental age, location of the household, and minority ethnicity, families with a child with ASD had lower family income than before the birth of the child. On average, having a child with ASD led to a 14% decrease in family income (Montes and Halterman, 2008). Lower family income could be an indication as to why parents sought diagnoses through the public health system as opposed to paying for private assessments.

Health Belief Model

Threat expectation. It was predicted that parents of children diagnosed with ASD at or before 30 months of age would perceive a greater threat of their children having a developmental disorder and that the threat of a developmental disorder to their children's future outcomes (e.g., school performance, social interactions) would be

perceived as more serious than parents of children diagnosed with ASD later than 30 months of age. These hypotheses were not supported. Parents from both the early and the later diagnoses groups indicated that the time of their initial concerns about their children's development, they perceived there was *some* threat of their children having a developmental disorder and that the threat of a developmental disorder to their children's future outcomes was *somewhat* serious.

It was predicted that parents of children diagnosed with ASD at or before 30 months of age would perceive they had a greater knowledge about child development and a greater knowledge about ASD than parents of children diagnosed with ASD later than 30 months of age. These hypotheses were not supported. Parents from both the early and the later diagnoses groups indicated that the time of their initial concerns about their children's development, they had *some* knowledge about child development and *little* knowledge about ASD. Perhaps environmental cues or other people in their environment influenced their actions toward earlier diagnoses. For example, one parent of a child diagnosed at or before 30 months of age reported, "Actually, my fiancé's mother brought it to my attention that she may have had a little bit of concern."

Although the parent initially felt some threat to her child's development, once she had accessed more information, she was influenced to take immediate action. Sometimes parents may be cued to action, but their help-seeking actions became delayed as they wait for appointments with various professionals. A parent of a child diagnosed with ASD later than 30 months of age reported:

I don't know, everything took forever to get there...
Waiting... the waiting is the worst. The not knowing... and then knowing, but (they) can't say anything to us... because it wasn't diagnosed; it had to be diagnosed by a doctor.

Parents had concerns for their children's development, but their help-seeking was either helped or hindered by people and events in their environment.

Parents reported that a number of different cues in their environment prompted them to be concerned about their children's development, including flyers, programs on the radio, television, or video about child development or ASD, workshops, and contact with other parents with children with developmental disabilities or ASD.

Perception of general self efficacy. It was predicted that parents of children diagnosed with ASD at or before 30 months of age would perceive greater general self-efficacy compared to parents of children diagnosed with ASD later than 30 months of age. This hypothesis was not supported. There was no significant difference between the early and the later diagnoses group; on average, both groups reported similar perceptions of general-self efficacy as indicated by their scores on the General Self-Efficacy Subscale of the Self-Efficacy Scale (SGSE; Sherer et al., 1982).

Perception of ability. It was predicted that parents of children diagnosed with ASD at or before 30 months of age would perceive a greater ability to decide what help their children needed, to find the help their children needed, and to get professionals to take action compared to parents of children diagnosed with ASD later than 30 months of age. This hypothesis was not supported. There was no significant difference between the early and the later diagnoses group; on average, both groups reported similar perceptions of *moderate* ability in all three areas. This could indicate that in general, parents feel they have the ability to do what needs to be done to help their children; the differences in the actual outcome (i.e., age at diagnoses) may be impacted more by systematic and clinician factors in their environment.

Analyses of Themes: Barriers and Benefits

Analyses of the qualitative data addressed the four interview questions: a) the factor that helped the most to help parents get their children diagnosed earlier; b) the factor that helped the least; c) anything else participant wanted to say about their experience getting the diagnoses; and d) the main factors that helped to get diagnoses of ASD. The interpretation of the data focused heavily on the factors parents perceived as barriers and benefits, elements of the HBM, influencing their experience obtaining diagnoses. Six central themes were identified that organize and summarize the results across these elements. These include: parent persistence/advocacy, physicians/paediatricians, other programs/professionals, relatives and friends, wait-time, and lack of knowledge.

Parent persistence/advocacy. The theme of parent persistence and advocacy emerged as one of the most common themes in parents' experiences obtaining diagnoses for their children. Almost half of parents reported that their own persistence was the main factor that helped them obtain diagnoses earlier for their children. Parents indicated that they had to persist to get help for their children when their physicians told them there was nothing wrong with their children. Getting answers to parents' questions or getting the necessary referrals to other professionals were the main benefits of being persistent. In addition, parents expressed the need to persist to provide their children with the benefits available from early intervention. For some parents, persistence entailed the sacrifice of paying for private diagnoses.

Physicians/paediatricians. The theme of physicians and paediatricians emerged as both a benefit and barrier in parents' experiences obtaining diagnoses for their children.

Benefits. For some parents, an appointment with their physicians or paediatricians provided the benefit of having concerns about their children's development brought into the forefront, provided parents with referrals to other professionals, and helped parents rule out other health or developmental possibilities. For other parents, a visit to their physicians or paediatricians provided the benefit of having their children's diagnoses confirmed and parents' questions and concerns addressed and explained providing them with the benefit of information and empowerment. One parent reported, "Just the willingness of the docs to explain and empower the parents with information... that was one of the big things."

Barriers. Physicians and paediatricians were also viewed as a barrier to some parents. Parents expressed their frustration with their physicians' propensity to "explain away" their concerns, at times adding a further barrier for parents when they started to doubt themselves and their concerns about their children's symptoms. Parents reported their physicians saying, "There's nothing wrong, it's a typical boy behaviour," and "no, no, he's fine, he's just a little delayed. Other parents reported their physician "just kind of sloughed it off."

Other programs/professionals. The theme of other programs and professionals emerged as both benefit and barrier in parents' experiences obtaining diagnoses for their children

Benefits. Some parents indicated the benefit of having speech and language pathologists and occupational therapists already involved with their children. These professionals were not only able to provide parents with much needed services, they were also able to provide parents with information and direction as to where to go next to find answers for their children's developmental concerns. Several parents indicated that staff members or professionals from early intervention agencies were the most beneficial factor in the process of obtaining diagnoses for their children.

Barriers. Some parents found professionals created barriers for them in that the professionals were not able to understand or connect with their children, or they did not recognize their children's difficulties. Further barriers were created by long waitlists for services or referrals to see other professionals.

Family and friends. The theme of family and friends emerged as both a benefit and a barrier in parents' experiences obtaining diagnoses for their children.

Benefits. Extended family members provided some parents with the benefit of recognizing their children's delays or bringing symptoms and characteristics to parents' attention, thus making them aware there was a threat. One parent indicated that another family member who was also the parent of a child with ASD was the most beneficial factor in her attempt to get help. The benefit of talking to the family member helped to encourage her to move forward quickly to get a diagnosis and intervention for her child.

Barriers. Some parents perceived family and friends as barriers to their attempts to get answers and obtain diagnoses for their children. When asked to indicate the factor that they would consider being the least helpful in their experience of obtaining a diagnosis for their child, one parent replied:

So sad to say it, I think it was my family and friends ... Like early on, before we were even thinking of diagnosing him or taking him for any assessments... A lot of people said 'oh he's a boy and don't forget he's a twin and he's a preemie...' A lot of family and friends were trying to comfort and to reassure us that he was okay, but made us have that little time of , period of,... second thoughts, 'well maybe he is okay, maybe we are doing this all for nothing' ...

Other parents expressed similar experiences of family members, friends, or colleagues creating doubt in their minds and causing them to second guess themselves. One parent stated, "If I had probably listened to them, I would not be where I am right now."

Wait times. The theme of wait times emerged as a barrier in parents' experiences obtaining diagnoses for their children. Parents expressed their frustration in having to be on long waitlists. Waitlists were perceived as a barrier to getting services their children needed to obtain diagnoses or to get intervention. One parent indicated that waitlists were the least helpful factor in helping her get a diagnosis for her child:

Long waiting lists for everything to get assessed... for various things ahhhh.... there was a list to get into a walk-in clinic for the communication program that our city has, but after you got accepted, there is a huge waiting list to actually get a formal assessment, and then once you got that and then, they decided that he would be better served by a children's treatment centre instead of this communication thing and there was a huge waiting list for that....

Lack of knowledge. The theme of lack of knowledge emerged as a barrier in parents' experiences obtaining diagnoses for their children. Some parents expressed their frustration in having to push to get referrals for their children because their family physicians lacked the knowledge to recognize symptoms and characteristics of ASD in their children. One parent who had eventually opted to pay for a private assessment and diagnosis stated, "I think part of the problem is he, um; I think some of the medical doctors aren't uh educated on this, on autism..." In some cases, parents perceived these professionals as a barrier to getting to the professionals who could help them get their

children the help they needed, “So then I had gone back battling.... doctors, ‘I think you know, he needs to be seen’”

Other themes. Other recurrent themes included advice to parents of children just starting the process of seeking diagnoses for their children. Parents advised other parents to follow their instincts and intuitions because “you know your child.” They expressed the need for parents to be persistent and advocate for their children and the importance of not delaying, because early intervention is so important and waitlists are long.

Other recurrent themes included experiences and feelings. These included feelings of shock and denial:

I don’t know if my mind shut off like, she said autism but I, I remember having to say it because she started talking about autism like, she said high functioning autism and you like, there’s a lot of blah, blah, blah, but then I said to her, ‘wait a minute,’ I said, ‘are you saying he has that?’ Because I guess I missed it and then as she kept talking

Parents also expressed feelings of relief, being glad, and recognizing the benefits of finally having a diagnosis, “It was a great relief, because at least we knew now what we were dealing with.” For some parents, the relief of finally having the diagnoses validated their concerns and the actions they had taken to obtain the diagnoses, “I felt relieved once I had it; I felt that I knew I’d been on the right track and that I was observing....” Other parents stated they felt glad that they had followed through with their concerns and persisted because now they had a path to follow and they were able to access interventions for their children. Finally, one parent summed up her experience obtaining an early diagnosis for her child:

I think the biggest favour that we did for our son was, was getting him diagnosed early and not ignoring those early signs, um, he’s the amazing little kid that he is today, well you see him, like he’s just incredible and, and I seriously think that’s because it was so early when we started his therapy, so yeah, it’s all good now.

Limitations of the Current Study

There are several limitations to the present study that strongly impact generalization of the results. First, the sample for this study consisted primarily (96.6%) of parent members of Autism Ontario and parents associated with an Applied Behaviour Analysis Treatment centre for preschool children with ASD. Thus, the sample may not be representative of the wider population of Ontario or the wider population of parents with children with ASD. In addition, parents had the option of completing the questionnaire in four formats. It is possible that participants that chose to complete the questionnaire over the telephone, or in-person with the researcher may have responded differently to certain questions than participants who completed the questionnaire by mail or on-line. The sample size for this study was small, compromising statistical power. In addition, the range of children's ages may not have been wide enough to detect differences between groups (i.e., a large number of children clustered around 30 months of age). This study was retrospective, thus parents may have had to rely on memories that were up to 6 ½ years in the past. It is possible that some parents' estimation of dates or other temporal events were less accurate than others. Fortunately, some of these instances were clarified by the diagnostic reports parents were asked to provide as verification of their children's diagnoses. Parents' memories may also have been impacted by current experiences and knowledge concerning their children.

Implications

Findings from this research have important implications in the context of clinical practice and for increasing early diagnosis for children and families impacted by ASD. The current research suggests that the age of children at the time of initial concern in

regard to symptoms and characteristics of ASD is related to the age at diagnoses; therefore, increasing parents', the public's', and professional awareness of the early signs of ASD is critical. Furthermore, parents seem to be encountering barriers when they seek help for their concerns about their children's development from professionals. Increasing both physicians and other clinicians' understanding and awareness of the early signs and characteristics associated with ASD could lead them to *hear* parents' concerns about their children's development. This, in turn, could lead physicians to ask parents a broader range of questions, thereby increasing the potential to identify children with ASD at earlier ages. The American Academy of Pediatrics urged physicians to listen to parents' concerns in their 2000 guidelines to physicians (O'Keefe, 2000).

Future Directions

Research focused on improving methods to allow physicians and professionals such as speech and language pathologists to recognize the early signs of ASD in very young children are critical. Prospective studies have demonstrated that infants later diagnosed with ASD can be distinguished from typically developing infants and from other infant siblings as early as 12 months of age (Zwaigenbaum et al., 2005). Further, the combination of clinical judgement with standardized diagnostic tools has made it possible to reliably diagnose children with ASD between 18 and 24 months as evidenced by reliability and stability studies (e.g., Brian et al., 2008; Matson et al., 2008; Pandey et al., 2008; Wetherby et al., 2008; Zwaigenbaum, 2010). Finding ways to educate physicians and other professionals who typically come in contact with very young children to recognize the early signs and characteristics of ASD, and providing them with empirically based screening tools is essential to earlier identification of ASD. Therefore,

future research should focus on developing user friendly screening tools that capture the early signs and characteristics of ASD in very young children.

Another direction for future research is to investigate how community practices influence the identification and referral of children showing early signs and characteristics of ASD. Learning more about how professionals who typically come in contact with very young children (e.g., nurse clinicians, Occupational therapists, and speech and language pathologists) are educated about the early signs and characteristics of ASD and how they communicate and respond to parents when there are concerns, could lead to improved training practices, more referrals, and ultimately improved identification of ASD at very young ages.

It is also important to focus research on finding ways to educate parents on the risk factors relating to ASD as parents are often the first to become concerned about their children's development. Increasing parents' knowledge and awareness of the early signs of ASD and the impact having ASD can have on the future outcome of their children might lead parents to seek help earlier.

Conclusions

The present study investigated factors that influence parents toward early diagnosis of Autism Spectrum Disorder for their children. Although results from this research suggest children are currently being diagnosed at younger ages than reported in past research (e.g., Howlin & Moore, 1997; Shattuck et al., 2009; Siklos & Kerns, 2007), improvements are still needed. Future research should focus on effective ways of educating parents about the risk factors of ASD, developing reliable and user friendly screening tools to allow physicians and other clinicians to better identify children at risk

for ASD as well as focus on educating and training front-line workers to recognize and assist parents to navigate toward earlier diagnoses of ASD.

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Appendices

Appendix A

Recruitment Flyer

Parents Needed for Research on Early Diagnosis of Autism Spectrum Disorder (ASD)

Are you a parent of a young child with a diagnosis of ASD?

We would like to know what **helped you get an early diagnosis for your child.**



We are conducting a study to learn what helps parents get an early diagnosis of ASD for their children.

Who can participate:

- Parents and/or Guardians of a child under 6 1/2 years of age diagnosed with an Autism Spectrum Disorder

If you participate, you will be asked to:

1. Complete **one** questionnaire. You can complete the questionnaire either:

by telephone  in person  or by the mail  =

For participating, you will be offered a \$5 Tim Horton's gift card



OR on-line  = <http://www.uwindsor.ca/parent>

For participating, you will be offered a chance to enter a draw for a \$50 gift card to Tim Horton's, Toys R Us, or Chapters



2. Provide a copy of your child's diagnostic report

All information is confidential. You can withdraw participation at any time.

For more information, **please contact:**

Debra Barrie, B.A. Honours, Masters Candidate
barried@uwindsor.ca OR (519) 973-8746



This research is being supervised by: Marcia Gagg, Ph.D, University of Windsor
maragg@uwindsor.ca

This study has received clearance from The University of Windsor's Research Ethics Board

Appendix B

Email to Autism Ontario Chapters

Hello _____,

I am a graduate student at the University of Windsor in Child Clinical Psychology. I am collecting data for my Master's thesis, entitled "*Factors Influencing Parents Toward Early Diagnosis of Autism Spectrum Disorders.*" The purpose of this study is to look at what helps parents get an early diagnosis of ASD for their children. I would like to know about parents' first concerns about their children's development, what parents did to get professional help, and what helped parents obtain a diagnosis.

I would like to ask permission to post a flyer about my research on insert organization's name website. I am asking research participants to complete an on-line questionnaire that takes approximately 20-30 minutes and to supply a copy of their child's diagnostic report (to be shredded once diagnosis has been verified).

I have attached a copy of the Research Ethics Board clearance for this research and the REB approved on-line flyer outlining the purpose of the research and how interested subjects may participate. The research questionnaire is accessible at <http://www.uwindsor.ca>

I am presently collecting data and will continue to collect data until August 1, 2010.

Thank you for considering my submission. Your assistance is greatly appreciated.

Sincerely,

Debra Barrie, B.A.
Master's Candidate, Child Clinical Psychology
University of Windsor

Appendix C

Letter to Autism Ontario Chapters



I am a graduate student at the University of Windsor in Child Clinical Psychology. I am collecting data for my Master's thesis, entitled "*Factors Influencing Parents Toward Early Diagnosis of Autism Spectrum Disorders.*" The study looks at parents concerns about their children's development and what helped them to get diagnoses of ASD for their children early.

To ensure that parents in other areas of Ontario are represented in the research, I have included 10 questionnaire packages. The questionnaire takes approximately 30 minutes to complete. I would really appreciate if you could forward these packages to families who reside in the **(INSERT NAME OF CHAPTER AREA)** area who have a child under the age of 6 ½ years of age with a diagnosis of an autism spectrum disorder. As a thank you, parents who participate will be offered a \$5 Tim Horton's gift card.

Please contact me if you have any questions. Your assistance is greatly appreciated.

Sincerely,

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Appendix D

On-line Recruitment Flyer



Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder

Research participants needed

- ❖ Are you the parent of a child diagnosed with an Autism Spectrum Disorder?
- ❖ Is your child with Autism Spectrum Disorder under 6 1/2 years of age?
- ❖ Do you live in Ontario?

I am a graduate student from the University of Windsor completing my Master's degree in Child Clinical Psychology.

The purpose of this study is to look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

Participants will be required to:

1. Complete an on-line questionnaire that takes approximately 30 minutes to complete
2. Provide a copy of the diagnostic report or complete a 'Consent to Release Information' form to allow the researcher to obtain the report from the diagnosing clinician. The form and a stamped, pre-addressed envelope will be provided for this purpose

On-line Participants have the opportunity to enter a **Draw for a \$50 gift card** of their choice of Tim Horton's, Toys R Us, or Chapters.

****Participation is limited to families living in Ontario.*

This research has received ethics clearance from the University of Windsor's Research Ethics Board (REB# 10-032).

You can access the study at: <http://www.uwindsor.ca/parent>

If you are interested in learning more about the study, please contact [Debra Barrie](#) at 519-973-8746, or email barried@uwindsor.ca

Appendix E

Help Seeking Questionnaire

Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder

This study is about your experiences throughout your journey toward your child's diagnosis of an Autism Spectrum Disorder. Please tell us what **you think** helped you to obtain your child's diagnosis.

Please complete the following information about **your child**.

1. **Your child's birth date:** Year _____ Month _____

2. **Is your child a** a) Boy or b) Girl

3. **Child's birthplace:** City _____ Province _____ Country _____

4. **Your child's first language:**
 - a) English
 - b) French
 - c) Other (Please Specify) _____

5. **Does your child have any other disorders or medical conditions?**
 Yes (Please Specify) _____ No

First Concerns:

Please think back to **before** your child received the diagnosis when answering the following questions:

6. Who first became concerned about your child's development?

- a) You
- b) Family member (e.g., father, grandmother - Please specify) _____
- c) Another parent
- d) Child care provider (e.g., day-care or preschool staff - Please specify) _____
- e) Clinician (e.g., family doctor, paediatrician, speech pathologist – Please specify) _____
- f) Other (Please specify) _____

7. How old was your child when you first became concerned? Years ____ Months ____**8. What were your first concerns? (Check all that apply)**

- a) Language Ability – Specific concerns _____
- b) Social Skills– Specific concerns _____
- c) Behaviour issues – Specific concerns _____
- d) Medical concerns/delays – Specific concerns _____
- e) Other — Specific concerns _____

9. What action(s) did you take when you first became concerned? (Check all applicable)

- a) Talked to friend about concerns
- b) Talked to child's educational staff (Please list staff position) _____
- c) Talked to someone at Early Years or similar program (Please list) _____
- d) Contacted family doctor
- e) Contacted speech and language professional
- f) Contacted audiologist
- g) Contacted another professional (Please list profession) _____
- h) Other _____

10. How old was your child at the time of first appointment regarding the concerns?

Years _____ Months _____

11. What professionals did you consult regarding the concerns?

	GENDER		Check who you consulted 1 st , 2 nd , etc					
	Male	Female	1st	2nd	3rd	4th	5th	6th
a) Family doctor								
b) Paediatrician								
c) Psychologist								
d) Psychiatrist								
e) Speech and Language Specialist								
f) Other (Please specify) _____								
g) Other (Please specify) _____								

12. What was the profession of the clinician who REFERRED you to the person who first diagnosed your child with an Autism Spectrum Disorder (ASD)?

- a) Referring clinician’s profession _____
- b) Referring clinician’s gender i) Male ii) Female

13. Think back to when you first became concerned about your child’s development. Please rate the following statements as how concerned you would have been at that time.

	1 none	2 little	3 some	4 moderate	5 very
13 a) The possibility of your child having a developmental disorder.	1	2	3	4	5
13 b) Your knowledge of child development at the time of your first concerns.	1	2	3	4	5
13 c) Your knowledge of autism at the time of your first concerns.	1	2	3	4	5
13 d) The threat of your child’s condition to future developmental outcomes. (e.g., school performance, making friends, etc.)	1	2	3	4	5

14. Think back to when you **first became concerned**.

What **actions** did you **think** of taking?

What **barriers** did you see for each action?

What **benefits** did you see for each action?

Possible Action (e.g., wait and see, do some research, talk to friend, talk to family doctor)	Barriers to Action	Benefits of Action
a)		
b)		
c)		
d)		

*You may not require all of the space provided, but please use the back of the page if you need more space.

15. Sometimes parents become aware of concerns about their children because of something they hear, see, or experience. Were any of these true for you? (Please check all applicable)

- a) Poster or flyer on child development. Where? _____
- b) Television ad or program on child development
- c) Radio ad or program on child development
- d) Video ad or program on child development. Where? _____
- e) Workshop or presentation on child development. Where? _____
- f) Television ad or program/promotion on Autism
- g) Radio ad or program/promotion on Autism
- h) Video ad or program/promotion on Autism. Where? _____
- i) Workshop or presentation on Autism - Where? _____
- j) Knew someone with a child with a Developmental Disability
- k) Knew someone with a child with an Autism Spectrum Disorder
- l) Knew someone who was concerned about their child's development
- m) Other _____

First Diagnosis:

16. How old was your child at time of first ASD diagnosis?

Years _____ Months _____

17. What specific *first* diagnosis was your child given?

- a) Autism or Autistic Disorder
- b) Asperger's Disorder
- c) Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- d) Other _____

18. Please think back to the clinicians you saw during the diagnosis process. Answer the following questions regarding the *first* clinician that gave an ASD diagnosis for your child.

a) What was the *first* diagnosing clinician's name: Dr. _____

b) Gender of *first* diagnosing clinician: i) Male ii) Female

c) Profession of the diagnosing clinician:

- i) Family doctor
- ii) Paediatricians
- iii) Psychologist
- iv) Psychiatrist
- v) Others (Please list) _____

d) Where did this diagnosing clinician work:

- i) Private practice
- ii) Private clinic
- iii) Walk-in clinic
- iv) Hospital clinic/office
- v) Clinician affiliated with an organization (e.g., Early Years program, Behavioural Intervention Program)
- vi) Other (Please specify) _____

e) Did you pay a fee for the first diagnosis?

- i) Yes
- ii) No

19. How long did you have to travel to reach the clinician?

- Less than 15 minutes
- 15 to 30 minutes
- 31 to 60 minutes
- 61 to 90 minutes
- 91 to 120 minutes
- Over 2 hours

20. What were the main factors that helped you to get an ASD diagnosis earlier for your child?

*Please use the back of the page if you need more space.

21. The following are a series of statements about your personal attitudes and traits. Each statement represents a commonly held belief. (with permission: Sherer et al. 1982)

Read each statement and decide to what extent it describes you. There are no right or wrong answers. You will probably agree with some of the statements and disagree with others.

Please indicate your own personal feelings about each statement below by marking the letter that best describes your attitude or feeling.

When answering these statements, please think back to **before** your child received the diagnosis and answer as you would have answered **at that time**. Please be very truthful and describe yourself as you really were, not as you would like to have been.

	A disagree strongly	B disagree moderately	C neither agree or disagree	D agree moderately	E agree strongly
21 a) When I make plans, I am certain I can make them work.	A	B	C	D	E
21 b) One of my problems is that I cannot get down to work when I should.	A	B	C	D	E
21 c) If I can't do a job the first time, I keep trying until I can.	A	B	C	D	E
21 d) When I set important goals for myself, I rarely achieve them.	A	B	C	D	E
21 e) I give up on things before completing them.	A	B	C	D	E
21 f) I avoid facing difficulties.	A	B	C	D	E

	A disagree strongly	B disagree moderately	C neither agree or disagree	D agree moderately	E agree strongly
21 g) If something looks too complicated, I will not even bother to try it.	A	B	C	D	E
21 h) When I have something unpleasant to do, I stick to it until I finish it.	A	B	C	D	E
21 i) When I decide to do something, I go right to work on it.	A	B	C	D	E
21 j) When trying to learn something new, I soon give up if I am not initially successful.	A	B	C	D	E
21 k) When unexpected problems occur, I don't handle them well.	A	B	C	D	E
21 l) I avoid trying to learn new things when they look too difficult for me.	A	B	C	D	E
21 m) Failure just makes me try harder.	A	B	C	D	E
21 n) I feel insecure about my ability to do things.	A	B	C	D	E
21 o) I am a self-reliant person.	A	B	C	D	E
21 p) I give up easily	A	B	C	D	E
21 q) I do not seem capable of dealing with most problems that come up in life.	A	B	C	D	E

	A disagree strongly	B disagree moderately	C neither agree or disagree	D agree moderately	E agree strongly
22 a) I am confident in my ability to decide what help my child needs	A	B	C	D	E
22 b) I am confident in my ability to find the help my child needs.	A	B	C	D	E
22c) I am confident in my ability to get professionals to take action to get the help my child needs.	A	B	C	D	E

Please complete the following information about **you and your family**.

- 23. Your Gender:** a) Male b) Female
- 24. Your Age:** a) 18-34 years b) 35-44 c) 45-54 d) 55-64 e) 65+
- 25. Your Marital Status:**
- a) Single
 - b) Married and living with partner
 - c) Separated
 - d) Divorced
 - e) Widowed
- 26. Your relationship to child:**
- a) Biological Mother
 - b) Biological Father
 - c) Step-mother
 - d) Step-father
 - e) Adoptive Mother
 - f) Adoptive Father
 - g) Other (Please Specify) _____

27. How many **full or half siblings** are in the family: __ (Exclude child with early diagnosis of ASD)

Sibling	Age of Sibling	ASD Diagnosis? (Please specify)
1		
2		
3		
4		
5		

28. Which **race or ethnicity** do you identify with the most for yourself and for your child? (check one in each column)

You	Your Child	Race or Ethnicity
		a) Aboriginal
		b) Arab
		c) Black
		d) Chinese
		e) Filipino
		f) Japanese
		g) Korean
		h) Latin American
		i) South Asian (East Indian, Pakistani, Sri Lankan, etc.)
		j) Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese, etc.)
		k) West Asian (Afghan, Iranian, etc.)
		l) White/Caucasian
		m) Other (please specify): _____

29. **Your first language:**

- a) English
 b) French
 c) Other (Please Specify) _____

Child's other parent's first language:

- d) English
 e) French
 f) Other (Please Specify) _____
 g) Not Applicable

30. Your Education:

- a) High School or Less
- b) Some College/University
- c) Completed College/University
- d) Post-Graduate

31. Employment Status:

You: a) Full-Time b) Part-Time c) Unemployed d) Retired

Child's other parent:

- a) Full-Time b) Part-Time c) Unemployed
- d) Retired e) Not applicable

32. Your Household Income:

Before your child was diagnosed: Household income **now:**

- | | |
|--|--|
| a) <input type="checkbox"/> under \$25,000 | a) <input type="checkbox"/> under \$25,000 |
| b) <input type="checkbox"/> \$25,000 - \$49,999 | b) <input type="checkbox"/> \$25,000 - \$49,999 |
| c) <input type="checkbox"/> \$50,000 - \$74,999 | c) <input type="checkbox"/> \$50,000 - \$74,999 |
| d) <input type="checkbox"/> \$75,000 and over | d) <input type="checkbox"/> \$75,000 and over |
| e) <input type="checkbox"/> prefer not to answer | e) <input type="checkbox"/> prefer not to answer |

You are
finished.
Thank you!



Appendix F

In-Depth Interview

In-depth Interview

Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder

This study is about your experiences throughout your journey toward your child's diagnosis of an Autism Spectrum Disorder. I will be asking you some questions to further elaborate on the answers you gave us on the questionnaire you previously completed.

1. Tell me more about your first concerns about your child's development?
2. You indicated that your child has another disorder or medical condition. Do you think this made a difference in obtaining the diagnosis of ASD? How?
3. Tell me more about what you think were the main factors that helped you to get an ASD diagnosis earlier for your child?
4. What do you think helped you the most?
5. What do you think helped you the least?
6. Is there anything else you would like to tell me about your experience obtaining a diagnosis for your child?

You are
finished.
Thank you!



Appendix G

Face to Face Recruitment Script

Recruitment Script for Face-to-Face Recruitment

The primary researcher or the trained research assistant will offer the parent a recruitment flyer and say:

“We are gathering information to help us better understand what factors help parents to get an early diagnosis of Autism Spectrum Disorder for their children. Would you be interested in helping us out?”

If they are interested say:

“Do you have a child under 6 ½ years old with a diagnosis of Autism Spectrum Disorder?”

If they say yes, say:

“Do you have a preference as to how you would like to complete the questionnaire?”
(point to the four methods on the flyer).

If they say they would like to complete a paper copy, provide them with the questionnaire package containing the paper copy of the questionnaire.

If they say they would like to complete the questionnaire on-line – point out the website on the flyer.

If they say they would like to complete the questionnaire via telephone or face-to-face, ask them to print their name and a telephone number where you can contact them to arrange a time to complete the questionnaire with them. (Information from cards will be transferred to a master list that is stored in a locked filing cabinet. Once the card information has been transferred to the master list, the card will be shredded).

Then say:

“Thank you for taking the time to help me out.”

Appendix H

Letter of Information for Paper Questionnaire



LETTER OF INFORMATION AND CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire. This will take approximately 30 minutes.
- 2) Return the questionnaire and forms in the envelope provided.
- 3) Provide a copy of your child's diagnostic report.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you fill out a form with your name, phone number, and the address to where you want the gift card mailed. To protect your identity, we ask that you return the form sealed in the separate envelope that is provided along with the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your my child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply discard the questionnaire. If you would like to participate, complete the questionnaire and return it sealed in the stamped, addressed envelope that is provided. If after completing and returning the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Appendix I

Consent to Participate for Paper Questionnaire



CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire. This will take approximately 30 minutes.
- 2) Return the questionnaire and forms in the envelope provided.
- 3) Provide a copy of your child's diagnostic report.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you fill out a form with your name, phone number, and the address to where you want the gift card mailed. To protect your identity, we ask that you return the form sealed in the separate envelope that is provided along with the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your my child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply discard the questionnaire. If you would like to participate, complete the questionnaire and return it sealed in the stamped, addressed envelope that is provided. If after completing and returning the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

SIGNATURE OF RESEARCH PARTICIPANT

I understand the information provided for the study **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Appendix J

Consent to Release Information Form



Consent to Obtain/Release Information

I (We) _____ give permission for information
 (Print Full Name of Parent/Legal Guardian)

regarding _____
 (Print Full Name of Child) (Date of Birth)

To be shared between: Debra Barrie, University of Windsor, Dr. M Gragg, University of Windsor
 (Name of person, agency, or institution)

Name of Diagnosing Clinician: _____
 (Name of person, agency, or institution)

Address of Clinician: _____

Release: copy of records (specify) Copy of Diagnostic Report

I/we understand that the above information will be kept in strict confidence and will only be used for the purpose of the research study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD).

 (Signature of Parent of Legal Guardian) (Date)

 (Signature of Witness) (Date)

Expiry date: (please specify) _____ or September 30, 2010.


401 Sunset Avenue, Windsor, Ontario, Canada N9B 3P4 . tel. 519. 253.3000 fax: 519.973.7021 . website: www.uwindsor.ca/psychology

Appendix K

Thank You Form for Participants

Thank you for participating in our study.

We would like to offer you a \$5 Tim Horton's gift card as a thank you for participating. Please check the appropriate box below and return this card in the stamped, addressed envelope.

Yes, I would like to receive a gift card
 

No, I do not want to receive a gift card

Please send the gift card to:

Name: _____


Address: _____

Email: _____

I would be willing to provide further information in a telephone interview.

Yes (telephone number: (____ - ____ - _____))

No

University of Windsor 

Appendix L

Script for Booking Telephone Questionnaire

Telephone Script: Factors Influencing Parents Toward Early Diagnoses of ASD

(Script if arranging an interview time for Telephone Questionnaire)

Hi, may I speak with _____ (say parents' names) please?

Hi, _____ (say parents' names).

This is _____ from the University of Windsor.

You talked with _____ (say name of person they gave their contact information to) at the _____ (say name of event) about a study on Early Diagnoses of Autism Spectrum Disorder.

Can we arrange a time to do the questionnaire?

If **NO** –May we call you later?

If **YES** – We have _____ [go through schedule with parent].

When

is a good time for you?

Thanks, we'll call you then.

Appendix M

Script for Completing Telephone Questionnaire

Telephone Script: Factors Influencing Parents Toward Early Diagnoses of ASD

(Script if completing Questionnaire by Telephone)

Hi, may I speak with _____ (say parents' names) please?

Hi, _____ (say parents' names).

This is _____ from the University of Windsor calling about the Early Diagnoses study.

Is this still a good time to do the questionnaire?

If **NO** – When may I call back?

If **YES** - Great!

CONSENT FOR AUDIO-RECORDING

Read the following Verbatim:

To make sure we record your answers correctly, we would like to ask if it would be okay to audio-record your answers to the questionnaire.

You can choose to consent to the audio-recording or not and you are free to withdraw at any time by requesting that the recording be stopped. Your name (or your my child's name) will not be revealed to anyone and the recording will be kept confidential. Recordings are filed by Identification number only and stored in a locked cabinet. After the audio-recording has been transcribed and checked for accuracy the audio-recording will be deleted from the recorder. You can request a copy of the transcript be sent to you to allow you to check it for accuracy if you wish, just let me know if you want me to send you a copy.

Your confidentiality will be respected and the audio-recording will be for professional use only.

Do you give your permission to audio-record the interview?

If **NO** – That's OK, I will do my best to write down your answers as accurately as possible as you give them.

If **YES**- Great!

Start the audio recording State the Identification Number, and the date and time of the recording.

READ verbatim:

CONSENT TO PARTICIPATE IN RESEARCH

The Title of the Study is: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire by telephone. This will take approximately 30 minutes.
- 2) Provide a copy of your child's diagnostic report. A stamped, pre-addressed envelope will be provided.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your my child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. Any audio-recordings will be labelled with your Identification number. After the audio-recording has been transcribed and the transcription checked for accuracy, the audio-recording will be deleted. Any identifying information contained within the transcript will be deleted and replaced with your identification number. If you would like a copy of the transcript to verify it's accuracy, you can request this from the researcher at (519) 973-8746 or barried@uwindsor.ca. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the questionnaire with the researcher. If after completing the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

Do you understand the information provided for the study **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder**

We will send you a copy of the information I have just given you along with the Consent to Release Form and you Gift Card (if accepted). Please return the signed Consent to Release Form in the preaddressed, pre-stamped envelope we provide.

Do you have any questions?

Do you agree to participate in this study?

[start the questionnaire on the next page, reading it verbatim]

(Insert paper copy of questionnaire here)

Thank you for taking part in our study.

We'd like to offer you a \$5 Tim Horton' gift card for participating. Where can we send the card.

(Write down the address directly onto the prepared envelope).

We will also be sending you a copy of the Letter of Information we read to you earlier for you to keep.

As part of the study, you are asked to provide a copy of your child's diagnostic report. Do you have a copy you could send in a stamped, pre-addressed envelope we will send you? (If YES) Great, when you receive the gift card and Letter of Information, there will be a stamped, pre-addressed envelope enclosed as well. Just put the copy of the report in the envelope and put it in the mail. The copy of the diagnostic report will be shredded as soon as we have verified diagnostic information. Thanks so much.

(If NO) We'll send along a Consent to Release Information form for you to complete so we can get the diagnostic report directly from your clinician. Just complete and sign the form and return it in the stamped, pre-addressed envelope enclosed with your gift card.

Thanks for your help.

If you have any questions, please feel free to contact me/the researcher, Debra Barrie, or my/her supervisor, Dr. Marcia Gragg, Ph.D., C. Psych. Again, the contact information is in your package we will be sending to you.

Appendix N

Letter of Information for Telephone Questionnaire



LETTER OF INFORMATION TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire by telephone. This will take approximately 30 minutes.
- 2) Provide a copy of your child's diagnostic report. A stamped, pre-addressed envelope will be provided.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your my child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. Any audio-recordings will be labelled with your Identification number. After the audio-recording has been transcribed and the transcription checked for accuracy, the audio-recording will be deleted. Any identifying information contained within the transcript will be deleted and replaced with your identification number. If you would like a copy of the transcript to verify it's accuracy, you can request this from the researcher at (519) 973-8746 or barried@uwindsor.ca. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the questionnaire with the researcher. If after completing the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Appendix O

Script for Booking Face to Face Questionnaire

Telephone Script: Factors Influencing Parents Toward Early Diagnoses of ASD (Script if arranging an interview time for Face-to-Face Questionnaire completion)

Hi, may I speak with _____ (say parents' names) please?

Hi, _____ (say parents' names).

This is _____ from the University of Windsor.

You talked with _____ (say name of person they gave their contact information to) at the _____ (say name of event) about a study on Early Diagnoses of Autism Spectrum Disorder.

Can we arrange a time to do the questionnaire?

If **NO** –May we call you later?

If **YES** – We have _____ [go through schedule with parent].
When is a good time for you?

Would you like to do the interview in your home, or at the Summit Centre?

Great, what is your address? (write down their address on booking sheet)

Great, the Summit Centre is located at 940 Prince Road in Windsor, (if they ask: N9C 2Z5). Please come to the front door and ring the bell.

As part of the study, you are asked to provide a copy of your child's diagnostic report. Do you have a copy you could bring with you when we meet?

(If YES) Great. Thanks so much.

(If NO) We can have you sign a Consent to Release Information form if you are willing when we meet and we can get the diagnostic report directly from your clinician.

See you on _____ [restate date and time and location].

Thanks for helping us out.

Appendix P

Letter of Information for Face to Face Questionnaire



LETTER OF INFORMATION TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire with the researcher. This will take approximately 30 minutes.
- 2) Provide a copy of your child's diagnostic report.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your my child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. Any audio-recordings will be labelled with your Identification number. After the audio-recording has been transcribed and the transcription checked for accuracy, the audio-recording will be deleted. Any identifying information contained within the transcript will be deleted and replaced with your identification number. If you would like a copy of the transcript to verify its accuracy, you can request this from the researcher at (519) 973-8746 or barried@uwindsor.ca. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the questionnaire with the researcher.

If after completing the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Appendix Q

Consent to Participate for Face to Face Questionnaire



CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire with the researcher. This will take approximately 30 minutes.
- 2) Provide a copy of your child's diagnostic report.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your my child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. Any audio-recordings will be labelled with your Identification number. After the audio-recording has been transcribed and the transcription checked for accuracy, the audio-recording will be deleted. Any identifying information contained within the transcript will be deleted and replaced with your identification number. If you would like a copy of the transcript to verify it's accuracy, you can request this from the researcher at (519) 973-8746 or barried@uwindsor.ca. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the questionnaire with the researcher. If after completing the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

SIGNATURE OF RESEARCH PARTICIPANT

I understand the information provided for the study **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Appendix R

Consent to Audio-Record



CONSENT FOR AUDIO-RECORDING

Title of the Project: **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder**

Research Participant's Name: _____

I consent to the audio-recording of interviews between me and the primary Investigator or a Research Assistant.

I understand that this is voluntary and that I am free to withdraw at any time by requesting that the recording be stopped. I also understand that my name (or my my child's name) will not be revealed to anyone and that recording will be kept confidential. Recordings are filed by Identification number only and stored in a locked cabinet. After the audio-recording has been transcribed and checked for accuracy the audio-recording will be deleted from the recorder. Any identifying information in the transcript will be replaced with the Identification number.

I understand that confidentiality will be respected and that the audio-recording will be for professional use only.

(Signature of Research Participant)

(Date)

Appendix S

Script for Face to Face Questionnaire

Face-to-Face Script: Factors Influencing Parents Toward Early Diagnoses of ASD

(Script if completing Questionnaire in-person)

Hi, _____ (say parent's name).

I'm _____ (say your name). Did you find the place okay? (Respond to any small-talk the participant engages in while taking the participant to the room where you will be doing the questionnaire).

Once seated and participant is comfortable say:

Great! Let's get started.

CONSENT FOR AUDIO-RECORDING

Give the participant a copy of the Consent to Audio-Record form then Read the following Verbatim:

To make sure we record your answers correctly, we would like to ask if it would be okay to audio-record your answers to the questionnaire.

You can choose to consent to the audio-recording or not and you are free to withdraw at any time by requesting that the recording be stopped. Your name (or your my child's name) will not be revealed to anyone and the recording will be kept confidential. Recordings are filed by Identification number only and stored in a locked cabinet. After the audio-recording has been transcribed and checked for accuracy the audio-recording will be deleted from the recorder. You can request a copy of the transcript be sent to you to allow you to check it for accuracy if you wish, just let me know if you want me to send you a copy.

Your confidentiality will be respected and the audio-recording will be for professional use only.

Do you give your permission to audio-record the interview?

If **NO** – That’s OK, I will do my best to write down your answers as accurately as possible as you give them.

If **YES**- Great! Show them where to sign

Start the audio recording State the Identification Number, and the date and time of the recording.

Give a copy of the Consent to Participate form to the participant then READ verbatim:

CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master’s degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child’s development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire with the researcher. This will take approximately 30 minutes.
- 2) Provide a copy of your child’s diagnostic report.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your child's name will be kept in a secure place separate from the questionnaire. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. Any audio-recordings will be labelled with your Identification number. After the audio-recording has been transcribed and the transcription checked for accuracy, the audio-recording will be deleted. Any identifying information contained within the transcript will be deleted and replaced with your identification number. If you would like a copy of the transcript to verify its accuracy, you can request this from the researcher at (519) 973-8746 or barried@uwindSOR.ca. The researchers will keep the data from this study locked in a secure location for 7 years after the study is completed. All data and forms will be shredded or deleted after 7 years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the questionnaire with the researcher. If after completing the questionnaire you decide to remove the information that you provided on the questionnaire from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

Do you understand the information provided for the study **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder**

Do you have any questions?

Do you agree to participate in this study? [show participant where to sign the form if they consent to participate]

[start the questionnaire on the next page, reading it verbatim]

(insert paper copy of questionnaire here)

Thank you for taking part in our study.

We'd like to offer you a \$5 Tim Horton' gift card for participating.

(Give them the gift card if they choose to accept it).

As part of the study, you were asked to provide a copy of your child's diagnostic report. Do you have a copy with you? (If YES) Great.Thanks so much.

(If NO) Would you mind completing and signing a Consent to Release Information form so we can get the diagnostic report directly from your clinician?

If YES, give them the form)

(If NO, say that' okay)

Thanks for your help.

If you have any questions, please feel free to contact me/the researcher, Debra Barrie, or my/her supervisor, Dr. Marcia Gragg, Ph.D., C. Psych. Again, the contact information is in your package we will be sending to you.

(Go with them and show them out of the building. Of if it was at their home, leave).

Appendix T

Consent to Participate for On-line Questionnaire



LETTER OF INFORMATION AND CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete a questionnaire on-line. This will take approximately 30 minutes.
- 2) Provide a copy of your child's diagnostic report. The researcher will mail you a pre-stamped, preaddressed envelope for this purpose.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you the opportunity to enter a draw for a \$50 gift card. You will have the option of choosing a gift card to Tim Horton's, Toys R Us, or Chapters. If you are the winner of the gift card it will be mailed to the address you provide on the Draw Form by September 30, 2010.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. Your names will not appear in any reports of this study. Any forms or paperwork containing your name or your my child's name will be kept in a secure place separate from the questionnaire data. Diagnostic Reports will be shredded immediately after the diagnostic details have been verified. The researchers will keep the data from this study locked in a secure location for seven years after the study is completed. All data and forms will be shredded or deleted after seven years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time **before** you submit your questionnaire on-line without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study. Once you have submitted your questionnaire, you will **no longer** be able to withdraw your information as there is no way to identify and locate your specific questionnaire.

If you do not wish to take part in the study once you have started, simply exit the questionnaire. You will be sent directly to the Draw page and you can enter the Draw even if you choose to withdraw from the study. If you would like to participate, complete the questionnaire and submit it. You will be sent directly to the Draw page after you have clicked submit.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

SIGNATURE OF RESEARCH PARTICIPANT

I understand the information provided for the study **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study.

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

_____ Will be electronically inserted on online copy _____

Signature of Investigator

Date

Click to Consent

Click to Decline

Click to Print a copy of the Letter of Information and Consent to Participate for your records

Appendix U**On-line Draw Card****Thank you for participating in our study.**

You have been entered into the Draw for the \$50 gift card to either Tim Horton's, Toys R Us, or Chapters.



*****Please complete and return** the enclosed "Consent to Release Information" form and return it in the stamped, pre-addressed envelope provided. If you prefer to send a copy of your child's Diagnostic Report in place of signing the Consent to Release Information form, please return the report in the stamped, pre-addressed envelope instead.

Thank You for Participating



Appendix V

Letter to Diagnosing Clinician



Date

To: Name of Clinician

Address of Clinician

Dear:

Name of participant has volunteered to participate in a research study on how parents obtain an Autism Spectrum Disorder diagnosis for their children at younger ages. Name of participant reported that you diagnosed (his or her) child with an Autism Spectrum Disorder and has given permission to release a copy of name of child diagnostic report. A completed and signed Consent to Release Information form is enclosed.

For your convenience, a stamped, pre-addressed envelope has been provided for return of the report. Please inform us if there is a cost involved in obtaining a copy of the report.

Please contact me if you have any questions. Your assistance is greatly appreciated.

Sincerely,

Debra Barrie, B. A. Hon.
M. A. Candidate Clinical Psychology
University of Windsor
Department of Psychology
401 Sunset Avenue
Windsor, ON
N9B 3P4
barried@uwindsor.ca

Dr. Marcia Gragg, Ph.D., C. Psych
Faculty Supervisor
University of Windsor
Department of Psychology
401 Sunset Avenue
Windsor, ON
N9B 3P4
mragg@uwindsor.ca

Appendix W

Script for Booking In-Depth Interview

Telephone Script: Factors Influencing Parents Toward Early Diagnoses of ASD

(Script if arranging an In-Depth interview time)

Hi, may I speak with _____ (say parents' names) please?

Hi, _____ (say parents' names).

This is _____ from the University of Windsor. We would like to thank you for completing our questionnaire on things that help parents get an early diagnosis for their children.

You indicated you would be interested in providing more information if we needed it.

Can we arrange a time to do the interview?

If **NO** –May we call you later?

If **YES** – We have _____ [go through schedule with parent].
When is a good time for you?

Appendix X

Script for In-depth Interview

Telephone Script: Factors Influencing Parents Toward Early Diagnoses of ASD

(Script if completing In-Depth Interview by Telephone)

Hi, may I speak with _____ (say parents' names) please?

Hi, _____ (say parents' names).

This is _____ from the University of Windsor calling about the Early Diagnoses study.

Is this still a good time to do the questionnaire?

If **NO** – When may I call back?

If **YES** - Great!

CONSENT FOR AUDIO-RECORDING

Read the following Verbatim

To make sure we record your answers correctly, we would like to ask if it would be okay to audio-record your answers to the questionnaire.

You can choose to consent to the audio-recording or not and you are free to withdraw at any time by requesting that the recording be stopped. Your name (or your my child's name) will not be revealed to anyone and the recording will be kept confidential. Recordings are filed by Identification number only and stored in a locked cabinet. After the audio-recording has been transcribed and checked for accuracy the audio-recording will be deleted from the recorder. You can request a copy of the transcript be sent to you to allow you to check it for accuracy if you wish, just let me know if you want me to send you a copy.

Your confidentiality will be respected and the audio-recording will be for professional use only.

Do you give your permission to audio-record the interview?

If **NO** – That’s OK, I will do my best to write down your answers as accurately as possible as you give them.

If **YES**- Great!

Start the audio recording State the Identification Number, and the date and time of the recording.

READ verbatim:

CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master’s degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child’s development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete an interview with the researcher by telephone. This will take approximately 20 minutes.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

Any information gathered in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. An Identification number will be assigned to your questionnaire. A master list will be created linking your Identification number to your name to allow the researcher to locate your information should you choose to withdraw your information from the study. Your names will not appear in any reports of this study. Any forms or paperwork, such as the master list, containing your name or your child's name will be kept in a secure place separate from the questionnaire. Any audio-recordings will be labelled with your Identification number. After the audio-recording has been transcribed and the transcription checked for accuracy, the audio-recording will be deleted. Any identifying information contained within the transcript will be deleted and replaced with your identification number. If you would like a copy of the transcript to verify its accuracy, you can request this from the researcher at (519) 973-8746 or barried@uwindsor.ca. The researchers will keep the data from this study locked in a secure location for seven years after the study is completed. All data and forms will be shredded or deleted after seven years.

We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and remain in the study.

If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the interview with the researcher. If after completing the interview you decide to remove the information that you provided from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

A brief summary of the results of the research will be available by September 30, 2010 and will be posted on-line at <http://www.uwindsor.ca/autism>

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4, (519-253-3000, Ext. 3948), email: ethics@uwindsor.ca

Do you understand the information provided for the study **Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder**

We will send you a copy of the information I have just given you along with the Consent to Release Form and you Gift Card (if accepted). Please return the signed Consent to Release Form in the preaddressed, pre-stamped envelope we provide.

Do you have any questions?

Do you agree to participate in this study?

[start the Interview, reading questions verbatim. Record the participant`s answers word for word.]

In-depth Interview

Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder

This study is about your experiences throughout your journey toward your child`s diagnosis of an Autism Spectrum Disorder. I will be asking you some questions to further elaborate on the answers you gave us on the questionnaire you previously completed.

1. **Tell me more about your first concerns about your child's development?**
2. **You indicated that your child has another disorder or medical condition. Do you think this made a difference in obtaining the diagnosis of ASD? How?**
3. **Tell me more about what you think were the main factors that helped you to get an ASD diagnosis earlier for your child?**
4. **What do you think helped you the most?**
5. **What do you think helped you the least?**
6. **Is there anything else you would like to tell me about your experience obtaining a diagnosis for your child?**

You are finished. Thank you!

Thank you for taking part in our study.

We'd like to offer you a \$5 Tim Horton' gift card for participating. Where can we send the card.

(Write down the address directly onto the prepared envelope).

We will also be sending you a copy of the Letter of Information we read to you earlier for you to keep.

Thanks for your help.

If you have any questions, please feel free to contact me/the researcher, Debra Barrie, or my/her supervisor, Dr. Marcia Gragg, Ph.D., C. Psych. Again, the contact information is in your package we will be sending to you.

Appendix Y

Letter of Information for In-Depth Interview



LETTER OF INFORMATION TO PARTICIPATE IN RESEARCH

Title of Study: Factors that Influence Parents Toward Early Diagnosis of Autism Spectrum Disorder (ASD)

You are asked to participate in a study by Debra Barrie, B.A. Honours, from the Psychology Department at the University of Windsor as part of her Master's degree in Child Clinical Psychology.

Dr. Marcia Gragg, Ph.D., C. Psych., is supervising the study. If you have any questions or concerns, please feel free to contact Dr. Gragg at 253-3000, ext. 2227.

PURPOSE OF THE STUDY

The study will look at what helps parents get an early diagnosis of ASD for their children. I would like to know about your first concerns about your child's development, what you did to get professional help and what helped you obtain a diagnosis.

PROCEDURES

If you volunteer to participate in the study, you will be asked to:

- 1) Complete an interview with the researcher by telephone. This will take approximately 20 minutes.

POTENTIAL RISKS

You might feel mildly uncomfortable, anxious, or upset answering the questions as you recall the experiences you had obtaining a diagnosis for your child. You can access professional help by dialling the telephone code 211 or accessing the web address for 211Ontario <http://www.211ontario.ca> should you require help with psycho-emotional factors as a result of participating in the research.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will not directly benefit from taking part in the study. You will be giving us important information that might help us help future parents and children with ASD get early diagnoses. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

To thank you for participating in this study we offer you a five-dollar Tim Horton's gift card. To receive the gift card, we ask that you provide your name, phone number, and the address to where you want the gift card mailed. This information will be stored in a secure location separate from the research questionnaire.

CONFIDENTIALITY

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We may wish to use your information from this study in future research studies. Your information will still be confidential and identified only by an Identification number.

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If you do not wish to take part in the study, simply tell the researcher you do not wish to continue. If you would like to participate, complete the interview with the researcher. If

after completing the interview you decide to remove the information that you provided from the study, please contact Debra Barrie at (519) 973-8746 or barried@uwindsor.ca.

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SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Signature of Investigator

Date

Appendix Z

Request to Recruit at Summit Centre

From: Marcia Gragg <mgragg@uwindsor.ca>
Subject: Your request to recruit parents at Summit Centre - approved
Date: Mon, 1 Feb 2010 11:56:24 -0500
To: barried@webmail1.uwindsor.ca

HI Debra,

We approved your request to recruit parents at Summit Centre.

We ask you to;

- supply us with any hard copies of your flyer for parents that you want us to distribute
- supply us with an electronic copy of your flyer, if you want us to distribute it
- check on the Summit Centre website for dates of parent groups, workshops etc.
- give us 1 week notice of any Summit Centre event that you want to attend for recruitment
- give our Program Secretary Csilla a minimum of 2 days notice if you want to book a room
- rooms are most available on Thursdays, and any day after 3:15 p.m. On some other days and times, it might be possible for you to use a room.
- ask and reimburse Summit Centre for any Summit Centre resources that you use (photocopying, paper, etc.)

I will let you know if we have more factors for you to consider.

Good luck!

Marcia

Marcia Gragg, Ph.D., C.Psych.

Assistant Professor, Dept. of Psychology Clinical Director
 University of Windsor, 401 Sunset Ave. The Summit Centre for Preschool
 Windsor, ON N9B 3P4 Children with Autism
 phone 519-253-3000 ext. 2227 940 Prince Rd., Windsor, ON N9C 2Z5
 fax 519-973-7021 phone 519-255-1195 fax 519-255-9226
 email mgragg@uwindsor.ca website www.summitcentre.org
 website www.uwindsor.ca/autism
 INBOX Message <https://webmail1.uwindsor.ca/Session/172094-10T79hd1gSWVTxzb15Tq...>

Appendix AA**Permission to Use the SGSE Scale**

INBOX M ige

<https://webmail1.uwindsor.ca/Session/38874-ikldiQQH9kAoK3BdVB...>

From: "Sherer, Mark" <Mark.Sherer@memorialhermann.org>
Subject: RE: Request to use Gen. Self-Efficacy Scale - 1982
Date: Fri, 24 Jul 2009 07:33:47 -0500
To: <barried@uwindsor.ca>

I am writing to give you permission to use the Self-efficacy Scale in your research. I have attached a copy of the scale, scoring instructions, and a partial list of articles that have cited the scale. Good luck with your project.

Mark Sherer, Ph.D., ABPP-Cn
Director, Research and Neuropsychology
TIRR Memorial Hermann
Clinical Professor of Physical Medicine and Rehabilitation
Baylor College of Medicine
1333 Moursund
Houston, TX 77030

713-799-7007

713-799-7049 (fax)

TIRR
MEMORIAL
HERMANN
Rehabilitation & Research

Appendix BB

Permission to Publish the SGSE Scale



Confirmation Number: 2935400
Order Date: 08/26/2010

Customer Information

Customer: Debra Barrie
Account Number: 3000336080
Organization: University of Windsor
Email: barried@uwindsor.ca
Phone: +1 (519) 973-8746
Payment Method: Credit Card ending in 2006

Special Order Invoices billed to:
 Debra Barrie
 University of Windsor
 1021 Gladstone Avenue
 Windsor, ON N9A2R7

Order Details

Perceptual and motor skills
Order detail ID: 44142897

ISSN: 0031-5125
Publication Year: 1982
Publication Type: Journal
Publisher: AMMONS SCIENTIFIC LTD.
Rightsholder: AMMONS SCIENTIFIC, LTD.
Author/Editor: Mark Sherer et al, 1982

Permission Status: **Granted**
Permission type: Republish into a book, journal, newsletter...
Requested use: Dissertation
Republication title: FACTORS THAT INFLUENCE PARENTS TOWARD EARLY DIAGNOSIS OF AUTISM SPECTRUM DISORDER
Republication organization: UNIVERSITY OF WINDSOR
Organization status: Not for profit
Republication date: 10/01/2010
Circulation/Distribution: 10
Type of content: Selected pages
Description of requested content: 17 General Self Efficacy Questions from the GSE subscale of the Self Efficacy Scale
Page range(s): 666
Number of pages: 1
Requested content's publication date: 10/01/1982
Your reference: DEBRA'S MASTER'S THESIS, APPENDIX

Billing Status:
**Charged to
 Credit Card**

Rightsholder terms apply

Vita Auctoris

NAME: Debra Darlene Barrie

PLACE OF BIRTH: Waterloo, Ontario

YEAR OF BIRTH: 1960

EDUCATION: Waterloo Region District Secondary School
1974-1978

University of Guelph
2001-2007 (B.A. Honours)

University of Windsor
2008- 2010 M.A.