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Navigating the autism diagnostic system: Implications for earlier identification.

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NAVIGATING THE AUTISM DIAGNOSTIC SYSTEM: IMPLICATIONS FOR EARLIER IDENTIFICATION

by

Alison Ann Spadafora

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ABSTRACT

Autism Spectrum Disorders are characterized by repetitive, stereotyped behaviours and impairments in communication and socialization. The present research examined parents' experiences during the course of obtaining an autism diagnosis for their children. Participants, who resided throughout Ontario, were recruited through the Autism Society of Ontario and the Summit Centre Preschool for Children with Autism. The questionnaire was designed for the present research and focused on parents' initial concerns about their children's development and attempts at seeking professional help. By parent report, the children were diagnosed with Autistic Disorder (N = 52), Asperger's Disorder (N = 7) and PDD-NOS (N = 21). Results indicate that in 75% of cases, symptoms of autism were first identified by children's mothers at 19.71 months of age on average. The average amount of time that had passed between the age at which parents initially became concerned about their children's development and the age at the first appointment with a professional to address their concerns was 10.38 months. For the entire sample, the average age at diagnosis was 4.29 years of age and results of the research suggest that children are being diagnosed at younger ages over time. Child demographic variables (i.e., gender, ethnicity, birth order and socioeconomic status) did not significantly impact age at initial concern, the help-seeking delay and age at diagnosis. Parents believed that increasing medical doctors' knowledge about autism, decreasing the amount of time on waiting lists and having more professionals available to assess and diagnose autism would make the autism diagnostic system more efficient. Implications of the results for facilitating earlier diagnosis are discussed.

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INTRODUCTION

Overview

Context of the Problem

Autism Spectrum Disorders (ASD) are characterized by repetitive, stereotyped behaviours and pervasive impairments in communication and socialization. Individuals with autism experience life-long difficulties in daily living and often require support throughout adulthood (American Psychiatric Association [APA], 2000). Although ASD were once thought to be untreatable, intensive behavioural intervention utilizing applied behavioural analysis techniques has shown promise (e.g., Lovaas, 1987). Intensive behavioural intervention attempts to mitigate the degree of impairment, transform developmental outcomes and improve the level of functioning of children with ASD (e.g., Rogers, 1998). Approximately 50% of children who participate in intensive behavioural intervention programs demonstrate improvements in intelligence (e.g., Lovaas, 1987), school placement (e.g., Harris & Handleman, 2000), symptoms of autism (Sheinkopf & Siegel, 1998), problem behaviours (e.g., Smith, Eikeseth, Klevstrand & Lovaas, 1997) and adaptive ability (e.g., Anderson, Avery, DiPetro, Edwards & Christian, 1987).

For children with ASDs, the early years are an important period for optimizing developmental outcomes because intensive behavioural intervention is more effective when implemented at an early age (e.g., Harris & Handleman, 2000). Although autism can be diagnosed early through systematic infant screening, diagnosis is often delayed because fewer than 30% of health care practitioners routinely administer screening tests

(Filipek et al., 1999). The lack of systematic screening is disconcerting because researchers have demonstrated that infants who are later diagnosed with autism demonstrate symptoms in infancy, possibly as early as 6 months of age (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, Szatmari, 2005). Symptoms in infancy include, for example, lack of social smiling or maintaining eye contact that would be typical for developmental level and limited use of gestures (Filipek et al., 1999).

Researchers have demonstrated that parents of children who are later diagnosed with autism often have concerns about their child's development long before formal evaluations from professionals confirm a diagnosis (e.g., Volkmar, Stier & Cohen, 1985; Short & Schopler, 1988; Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997; De Giacomo & Fombonne, 1998; Baghdadi, Picot, Pascal, Pry, Aussilloux, 2003). That is, in the absence of routine screening procedures, symptoms of autism are usually first identified by children's primary caregivers within their home. After parents become concerned about their children's development, parents then begin the process of help-seeking from professionals to address their concerns (e.g. Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997; De Giacomo & Fombonne 1998). However, after parents voice their concerns about their children's language, social skills and behaviour, professionals rarely diagnose and often tell parents that there is no need to worry or take additional action (Howlin & Moore, 1997). Sometimes children are subsequently referred to a variety of professionals and this causes time delays due to waiting lists. Consequently, children are frequently diagnosed with autism late and these children are not only less likely to benefit from intensive behavioural intervention, they may even be ineligible for services (e.g., Ontario Ministry of Community, Family and Children's Services, 2002).

The present research will investigate parents' experiences during the course of obtaining an autism diagnosis for their children. Parents' initial concerns about the development of their children who were later diagnosed with autism will be examined to reveal what early symptoms are recognizable and most salient to parents. Next, parents' help-seeking behaviours will be investigated to identify informal sources of help that parents are utilizing and what parents believe are barriers to seeking help. The research will also address professionals' reactions to parents' concerns during the first, second and third appointment after parents became concerned about their children's development. Finally, parents' opinions about how to improve the autism diagnostic system will be explored. The overriding goal of the present research is to understand how the autism diagnostic system can be made more accessible to families and more efficient in diagnosing children as early as possible.

Organization of Review

The diagnostic criteria for ASD will be explained, including a brief discussion of relevant clinical features. Next, there will be a review of literature pertaining to symptoms of autism in infancy and a review of parents' initial concerns and their experiences during the course of obtaining an autism diagnosis for their children. Finally, there will be an examination of research regarding help-seeking by parents for their children's behaviour problems.

Definitional/Conceptual Issues

The umbrella term "autism spectrum disorders" includes several specific diagnoses (Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified) that share core characteristics: repetitive, stereotyped behaviours and pervasive impairments in communication and socialization (APA, 2000). Individuals with these disorders exhibit a range of symptom severity, from mild with minimal impairments, to severe with more pervasive impairments (Myhr, 1998). In order to capture the multi-dimensional quality of these disorders, the term "Autism Spectrum Disorder" is used colloquially in lieu of specific diagnostic categories, even though this term is not currently included in the *Diagnostic and Statistical Manual for Mental Disorders* (DSM-IV-TR; APA 2000; Szatmari, 2000). For the present research, the term "autism" or "autism spectrum disorders" will be used interchangeably to refer to individuals with Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified.

According to the DSM-IV-TR (APA, 2000), diagnostic criteria for Autistic Disorder include at least two impairments in social interaction, one impairment in communication and one restricted, stereotyped behaviour. Impairments in these areas must be present before age three to meet criteria for Autistic Disorder. For a diagnosis of Asperger's Disorder, restricted, stereotyped behaviours and deficits in socialization must be present, in the context of relatively intact cognitive and language skills. However, children are not diagnosed with Asperger's Disorder if criteria are met for Autistic Disorder (APA, 2000). Children are considered to have "atypical autism" or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) if symptom onset occurs after age three, symptom severity is at a sub-threshold level or symptoms are presented atypically. Diagnostic criteria for PDD-NOS are thought to be ill-defined because clinicians cannot reliably distinguish children who meet criteria for PDD-NOS from children who meet criteria for Autistic Disorder (Mahoney, Szatmari, MacLean, Bryson, Bartolucci, Walter, 1998; as cited in Szatmari, 2000).

Empirical Review

Clinical Features

Children with autism tend to demonstrate repetitive behaviours and stereotyped motor movements, such as hand-flapping or rocking (Klinger, Dawson & Renner, 2003). These behaviours are typically characteristic of lower functioning children with autism, and the presence of stereotyped motor movements is not specific to autism, as children with other developmental disabilities demonstrate these behaviours as well (Klinger, Dawson & Renner, 2003). Children with autism may become distressed by slight deviations from routines because they are more comfortable with predictability in their environment (Myhr, 1998). In addition, children with autism tend to have narrow, intense interests in specific people, things or activities, such as memorizing facts about a particular topic.

Although previous researchers found that approximately 50% of children with autism did not develop spoken language (APA, 2000), more children with autism are currently developing spoken language due to intensive early intervention. However, effectiveness of communication for children with autism who have spoken language is often impaired by echolalia, pronoun reversals (Klinger, Dawson & Renner, 2003) or abnormalities of intonation, pitch or rhythm (APA, 2000). They may also demonstrate difficulties in pragmatic language, which refers to the ability to use language for interpersonal communication in social situations (Myhr, 1998; Klinger, Dawson & Renner, 2003), and they may have trouble understanding non-literal communication, such as humor, sarcasm or irony (APA, 2000).

Children with autism have difficulty with non-verbal aspects of socialization. For example, they may not make eye-contact or attempt to direct their caregivers' attention to interesting objects through gestures or smiling (Filipek et al., 1999). They usually prefer to play alone in early childhood and although they may desire friendships in adolescence, their communication and socialization difficulties interfere with interpersonal relationships (APA, 2000). Children with autism have difficulty looking at the world from another person's perspective, referred to as deficits in "theory of mind" (Baron-Cohen, 1992). Because theory of mind deficits interfere with their ability to understand another person's perspective and anticipate behaviour, children with autism often have difficulty understanding social scenarios. Theory of mind deficits usually are not found in typically developing children older than age 3 or 4 (Klinger, Dawson & Renner, 2003) or in children with cognitive delays, suggesting that theory of mind deficits are specific to autism (Baron-Cohen, 1992).

Approximately 70% of children with autism have below-average cognitive skills (Fombonne, 2003). On standardized intelligence tests, they tend to have difficulty on tasks that involve encoding information in memory, shifting and disengaging attention, and executive functions, such as planning and organizing (Klinger, Dawson & Renner, 2003). Children with autism tend to have relatively intact rote memory skills and prolonged attention (Mash & Wolfe, 1999). Savant skills, or extraordinary abilities in specific areas such as memorization, music, arithmetic or art, are present in approximately 5% of children with autism.

Medical conditions are associated with autism in approximately 7% of cases, including Tuberous Sclerosis, Fragile X Syndrome, Cerebral Palsy, Phenylketonuria, Congenital Rubella, and Down's Syndrome (Fombonne, 2003). Also, approximately 25% of children with autism suffer from epileptic seizures that may increase in severity in adolescence. Genetic or prenatal factors may be involved in the etiology, as researchers have found evidence for brain abnormalities and abnormal elevations of neurotransmitters (Klinger, Dawson & Renner, 2003).

Males are approximately 4-5 times more likely to have autism than females; however, females with autism tend to have severe cognitive deficits (APA, 2000). The presence of severe cognitive deficits in females may explain why parents of females with autism report being concerned about their development earlier than do parents of males (Short & Schopler, 1988; De Giacomo & Fombonne, 1998).

The prevalence of Autistic Disorder is 9-11 per 10,000 people, the prevalence of Asperger's Disorder is 2.5 per 10,000 and the prevalence of all disorders along the autism spectrum is 27.5 per 10,000 (Fombonne, 2003). Population-based research in California found that from 1987 to 1994, the prevalence of autistic disorder increased significantly from approximately 6 to 15 per 10,000 people (Croen, Grether, Hoogstrate & Selvin, 2002). The authors identified several reasons for the increase, including enhanced community awareness, improved recognition of autism in children with mental retardation and a local trend of classifying children as having Autistic Disorder instead of Asperger's Disorder or PDD-NOS to enable eligibility for services. Currently, it is unknown whether these figures represent a true increase in incidence (Croen, Grether, Hoogstrate & Selvin, 2002).

Symptoms in Infancy

Early researchers who used home movies to investigate symptoms of autism in infancy found that before one year of age, children who are later diagnosed with autism demonstrate behaviours that can distinguish them from their typically-developing peers. Osterling and Dawson (1994) reviewed home movies of eleven typically-developing children and eleven children with autism who were selected from the University of Washington's Autism Research Program. Blind raters evaluated children's behaviour in the home videos by recording the number of social behaviours, emotional expressions, communications and actions of "joint attention" with caregivers. Infants who were later diagnosed with autism were less likely to engage in social behaviours and actions of joint attention with caregivers and they also demonstrated significantly more "autistic symptoms," such as not to attending to their name, engaging in self-stimulatory behaviours and covering their ears with their hands (Osterling & Dawson 1994). A more in-depth examination of the specific behaviours indicated that infants who were later diagnosed with autism were less likely than their typically developing peers to point to objects, show objects to others, look at faces, and attend to their name. The authors concluded that at one year of age, infants who were later diagnosed with autism could be behaviourally distinguished from their typically developing peers and suggested that screening procedures should be implemented to identify at-risk children.

Werner, Dawson, Osterling and Dinno (2000) extended these findings by using analysis of home movies to explore whether symptoms of autism could be detected prior to one year of age. All infants who were later diagnosed with autism from Osterling and Dawson's (1994) sample were included, plus 4 additional infants who were selected from the University of Washington's Autism Research Program. In total 8 children with a diagnosis of Autistic Disorder and 7 children with a diagnosis of PDD-NOS were included. The control group consisted of all typically developing infants from Osterling and Dawson's (1994) sample plus 4 additional typically developing infants. Initial analyses were not significant, indicating that infants later diagnosed with autism could not be behaviourally distinguished from typically developing infants based on their social behaviours, communication and repetitive actions at 8-10 months of age. After children with late-onset autism were omitted from analyses, infants later diagnosed with autism were less likely to engage in social behaviours, such as looking at faces and attending to their name. Discriminant function analyses revealed that 78% of children could be correctly classified according to the percentage of times they attended to their name. The authors concluded that as early as 8-10 months of age, infants who are later diagnosed with "early onset autism" can be distinguished from their typically developing peers, and that neglecting to attend to their name should be considered an early symptom of autism (Werner, Dawson, Osterling & Dinno, 2000).

Sensorimotor and social behaviours that distinguished between children with autism, children with developmental disabilities and typically developing children at 9-12 months of age were also investigated through analyses of home movies (Baranek, 1999). In total, there were 32 participants, including 11 children with autism, 10 children with developmental disabilities and 11 typically developing children. Blind raters analyzed home movies for the presence of behaviours in 12 categories, such as emotional expression and stereotyped interactions with objects. Children with autism were more likely than children with developmental disabilities and typically developing children to require name prompts from an adult, to place objects in their mouths, and to avoid physical contact, and they were less likely to pay attention to visual stimuli. Children with developmental delays were more likely than children with autism and typically developing children to demonstrate unusual posture, to play with objects in a stereotyped manner and to stare at visual objects, and they were less likely to look at the camera or display lively facial expressions. The authors concluded that early signs of autism are present in infancy and that these early signs can be distinguished from early signs of other developmental disabilities.

Currently, researchers who are examining early symptoms of autism are investigating infant siblings of children who have autism. This new research paradigm holds promise for identifying behaviours that can distinguish infants who are later diagnosed with autism from typically developing infants. Recent Canadian research indicates that symptoms of autism may be identifiable as early as six months of age (Zwaigenbaum et al., 2005). The on-going "Baby Sibs" research project is being conducted at the Children's Hospital in Hamilton, the Hospital for Sick Children in Toronto and the Autism Research Centre in Halifax. The researchers compared 65 infants who have siblings with autism (high-risk group) with a control group of 23 infants with no family history of autism (low-risk group) until 24 months of age. Several behaviours were examined, including visual disengagement, visual tracking, imitation, temperament, social behaviours and language skills. When infants were approximately 24 months of age, they were given a diagnostic assessment by a clinician who was blind to purpose of the research. Preliminary results indicate that infants in the high-risk group who were diagnosed with autism were found to be behaviourally distinguishable from infants who did not have autism. Specifically, infants who were later diagnosed with autism demonstrated a lack of social skills at six months of age (e.g., absence of imitation and attentiveness to others) and at 12 months of age (e.g., absence of vocalizations, eye contact and smiling). At 12 months of age, language skills were delayed and behavioral symptoms were present, including stereotyped toy-play, for example. In addition, at 12 months of age, infants who were later diagnosed with autism demonstrated more difficulties with visual disengagement compared to infants who do not have autism.

In summary, researchers have found that infants who are later diagnosed with autism do demonstrate symptoms in early infancy. As such, it is important to question which of these symptoms are noticed by parents and what parents do after becoming concerned about their children's development. A list of parent concerns that are "red flags" for autism was comprised by a Consensus Panel commissioned by the Child Neurology Society and the American Academy of Neurology based on a review over 2,500 journal articles (Filipek et al., 1999). Red flags for autism include communication concerns such as delayed language, inability to follow directions and acting as if deaf. Socialization concerns include solitary play, absence of age-appropriate social smiling and lack of eye contact. Behavioural concerns include the presence of tantrums, repetitive behaviours and toe walking. The absence of several behaviours in infancy are thought to be highly indicative of autism, including no gesturing or babbling by one year of age, no single-word speech by 16 months of age, and no phrase speech (i.e., unprompted 2-word combinations) by 24 months of age and the loss of any previously acquired skill, such as language or social behaviours (Filipek et al., 1999). The following is a review of parent concerns about the development of their children who were later diagnosed with autism and about their experiences obtaining professional help to address their concerns.

Initial Concerns as a Path to Diagnosis

Volkmar, Stier and Cohen (1985) investigated whether children diagnosed with Infantile Autism or Childhood Onset Pervasive Developmental Disorder according to DSM-III (1980) criteria could be reliably distinguished from one another based on assessment information. Participants included an archival group of 118 individuals (101 males, 17 females) between 3.8 and 30.2 years of age who were assessed over a period of 10 years at the Yale University School of Medicine. A record review revealed that more than 54% of parents were concerned about their children's development by one year of age and approximately 95% of parents were concerned by age two and a half. There were no significant relationships between age at initial concern and cognitive ability, parents' level of education, or the age at which children were evaluated.

Japanese researchers investigated the initial concerns of parents of 141 children (117 males and 24 females) with autism and 33 children with Mental Retardation who were enrolled at developmental disabilities treatment centers (Ohta, Nagai, Hara & Sasaki, 1987). The majority of parents of children with autism (57%) reported being concerned about their development between 18 and 30 months, however, the age at initial concern ranged from 6 months to approximately 4 years of age. The majority of parents of children with Mental Retardation (67%) were concerned about their children's development between 0 and 2 years of age, significantly earlier than parents of children with autism. The most common concerns reported by parents of children with autism were language (84%), followed by socialization (55%), hyperactivity (45%), acting as if deaf (32%) and inability to form relationships (26%). Parents of children with mental retardation also frequently reported concern about language (61%), however the majority of other concerns were for abnormal motor development. Furthermore, parents of children with autism were concerned significantly more often about their children's social development, and parents of children with mental retardation were concerned significantly more often about their children's motor development. Thus, parents of children with autism appear to have specific concerns about their children's social development, and concerns about social development should be investigated further by professionals to rule out autism.

Archival research was conducted on the age of symptom onset in a sample of children enrolled in the Division TEACCH (Treatment and Educations of Autistic and related Communication Handicaps) program at the University of North Carolina at Chapel Hill from 1970 to 1985 (Short & Schopler, 1988). Participants included 974 children (748 males and 231 females) who were diagnosed with autism according to their scores on the *Childhood Autism Rating Scale* (*CARS*; Schopler, Reichler & Renner, 1986) and 830 children (619 males and 211 females) who were not diagnosed with autism, but demonstrated impairments in communication and language. Short and Schopler (1988) found that approximately 76% of parents were concerned about their children's development by age 2 and 94% of parents were concerned by age 3. The average age at initial concern was approximately 18 months for females and approximately 20 months for males. In addition, parents of Caucasian children were concerned approximately 3 months earlier than were parents of African American children. Children whose parents became concerned before 30 months were found to have significantly lower IQ scores and significantly higher scores on the *CARS* than children whose parents became concerned after 30 months, indicating that parents tend to become concerned early for children with poor cognitive skills and more severe symptoms of autism. Thus, parents of children who are considered to be functioning higher on the autism spectrum may be concerned about their development later than parents of children who are lower-functioning. In Short and Schopler's (1988) sample, the majority of parents were concerned before age 3; however, as the average age of diagnosis was 6.6 years of age, it is apparent that parents of children with autism were concerned about their development for a lengthy period of time before an actual diagnosis was confirmed.

Rogers and DiLalla (1990) reviewed the records of 39 children (29 males and 10 females) who were assessed at a treatment clinic for children with autism in Colorado. Regarding concerns about social development, approximately 36% of parents were concerned by 12 months of age, 33% were concerned between 12 and 24 months of age and 28% were concerned after 24 months of age. There were no significant relationships between age at initial concern and gender, ethnicity, socioeconomic status, age at diagnosis, IQ or symptom severity, as measured by the *CARS* (Schopler, Reichler & Renner, 1986). On average, children entered treatment at 45.03 months of age and there were no significant relationships between age at admission and IQ.

Survey research was conducted in a sample of 128 parents who were members of the West Midlands Autistic Society in the United Kingdom on their experiences during the course of obtaining an autism diagnosis for their children (Smith, Chung & Vostanis, 1994). For statistical analyses, the sample was divided into two groups based on child age when the study was conducted: children aged 9 and younger (53 males and 8 females) and children aged 10-20 (53 males and 14 females). The researchers found that the age at which parents initially became concerned about their children's development was approximately 1.5 years of age for both groups of children. For children age 9 years and younger, the most common concerns were for delays in speaking (72%), unresponsiveness to others (61%) and a lack of imaginative play (51%) and for children age 10 years and older, the most common concerns were for unresponsiveness to others (64%), a lack of imaginative play (61%) and delays in speaking (54%). Parents reported seeking help for their children several months after initially becoming concerned, and this delay was approximately 3 months longer for parents of children in the older group. Children in the younger group first saw a professional at approximately 29 months of age on average in comparison to 43 months of age on average for children in the older group. Professionals provided similar advice to parents of children in both groups at the first consultation. Approximately 38% of children were referred to another specialist and 50% were told not to worry or take further action. At the first appointment, only 42% of children were diagnosed and, for the remainder of the sample, the amount of time required to obtain an autism diagnosis ranged from months to years. The average age at diagnosis for children in the younger group (43.5 months of age) was much earlier than the average age of diagnosis in the older group (82.7 months of age). Although children in the younger group were diagnosed 39 months earlier than children in the older group, the authors concluded that parents experienced difficulty obtaining diagnoses for their children and that the autism diagnostic system has not become more accessible and helpful over time.

Research on parents' experiences during the course of obtaining an autism diagnosis for their children was conducted in the United Kingdom (Howlin & Moore, 1997). Parents of children (1,077 males and 217 females) with ASD completed a questionnaire mailed from various autism support agencies to which they belonged. Although the sample consisted of parents of children who ranged in age from 2 to 49, the majority of children were between 5 and 10 years of age. Howlin and Moore (1997) found that the average age at initial concern was 1.69 years of age, however, the age at initial concern ranged from birth to 18 years of age. Approximately 16% of parents reported being concerned by their children's first birthday, 33% between the ages 1 and 2, and 49% between ages 2 and 5. More than 93% of parents reported being concerned about their children's development by age 3. Parents indicated that the majority of initial concerns were for language development (40.9%), followed by abnormal social development (19.3%) and general behavioural problems (12.7%). After becoming concerned about their children's development, parents waited an average of 6-7 months before seeking professional help. Approximately 25% of parents waited one year and 10% waited 2 years before seeking help. On average, children were 2.3 years of age when parents first sought help, however, children's ages when parents first sought help ranged from 1 month to 38 years of age (Howlin & Moore, 1997). At the first professional consultation (N = 1,295), the majority were referred for further evaluation (55.1%), or informed that there was nothing wrong with their children (25.0%). Even when parents reported concerns about behaviour, communication and socialization, only 7.8% of children were diagnosed with an autism spectrum disorder. The average age of children at the time of the second consultation was 3.34 years. By the second consultation (N =

1,174), 40.4% of children were diagnosed, 25.6% were referred and 13.5% of parents were told not to take further action. The average age of children at the time of the third consultation was 6 years. By the third consultation (N = 825), 63% of children were diagnosed, 12.6% were referred and 7% of parents were told not to take further action.

In Howlin & Moore's (1997) sample, the average age of diagnosis was 6.1 years of age. There was a trend for earlier diagnosis over time, children younger than age 10 were diagnosed at 3.7 years of age on average and children older than age 10 were diagnosed at 8.7 years of age on average. Approximately 50% of parents reported that they were not satisfied with the diagnostic process. The younger children were diagnosed, and similarly, the shorter the delay before diagnosis, the more satisfied parents were about the diagnostic process. Because parents of children who were diagnosed with Autistic Disorder were more satisfied than parents of children who were diagnosed with "autistic traits," or "tendencies," the authors recommended that professionals should not use those terms and should strive to provide unambiguous diagnoses. Howlin and Moore (1997) concluded that parents' concerns about their children's development should be considered seriously by professionals because a diagnosis of autism is required to enroll in treatment that will likely improve developmental outcomes.

Archival research was conducted on parents' concerns about their children's development and subsequent help seeking from professionals (De Giacomo & Fombonne 1998). Participants included parents of 82 children (70 males and 12 females) with ASD who were referred to Maudsley Hospital in England between 1993 and 1996. Children were administered the *Autism Diagnostic Interview-Revised (ADI-R*; Lord, Rutter & Le Couteur, 1994) and a standardized measure of cognitive ability. Parents completed intake interviews and the introduction section of the *ADI-R*, which involves asking parents about their concerns about their children's early development and help seeking behaviours. On the *ADI-R*, the most common concerns reported by parents were for speech and language development (74.4%), followed by abnormal socio-emotional response (39.0%), medical problem or delay in milestones (25.6%), general behavioural problems (25.6%) and autistic-type behaviours (14.6). In De Giacomo & Fombonne's (1998) sample, the average age of initial concern was 19.1 months, with 30% of parents becoming concerned by 12 months and 80% of parents becoming concerned by 24 months. Moreover, the average age of initial concern differed based on several child variables. Specifically, the average age of initial concern was earlier when concerns were for medical problems or delays in milestones than when concerns were for speech and language development. Parents of children with cognitive impairments were concerned earlier than parents of children without cognitive impairments. Although the average age of initial concern was earlier for females in comparison to males, this relationship was not significant, possibly as a result of small sample size. Parents with a typically-developing older child were concerned earlier than parents without older children, but this relationship was not significant, likely due to small sample size as well.

In De Giacomo and Fombonne's (1998) research, parents sought help when their children were 24.1 months of age on average, a 5.2 month delay after the average age of initial concern. Parents whose initial concerns were for a medical problem or a delay in milestones sought help earlier than parents whose initial concerns were in another area. Also, there was a non-significant trend for parents with older children to seek professional help earlier than parents of only children. De Giacomo and Fombonne

(1998) concluded that parents were able to detect their children's developmental abnormalities, and that identification of abnormalities was partially related to prior experience with child-rearing.

The relationship between age at initial concern and symptom severity was investigated in a sample of 193 children with an autism spectrum disorder who were recruited between 1997 and 1998 from child psychiatry clinics in France (Baghdadi, Picot, Pascal, Pry, Aussilloux, 2003). Participants (81.3% males and 18.7% females) were 5 years of age on average, ranging from 21 months to 7 years of age. Children were administered the *Vineland Adaptive Behavior Scales* (Sparrow, Balla & Cichetti, 1984) and the *Childhood Autism Rating* (Schopler, Reichler & Renner, 1986) to measure adaptive ability and symptom severity, respectively. Parents were also interviewed about their children's medical history, early development and demographic information. According to parent reports, the average age of initial concern was 17 months of age. Approximately 38% of parents reported being concerned by their children's first birthday, 40% between 12 and 24 months and 18.8% of parents reported becoming concerned between 24 and 36 months. Weak adaptive skills and more severe symptoms of autism were associated with earlier concern. Also, parents of children with medical, neurological, infectious or peri-natal conditions were concerned about their development earlier than parents of children who did not have such conditions. There were no significant relationships between child characteristics, such as gender, birth order and socioeconomic status, and the age at initial concern. Furthermore, auditory deficits and low scores on the Daily Living Skills domain of the *Vineland Adaptive Behaviour Scales* were the best predictors of concern before 18 months of age. Baghdadi et al. (2003)

concluded that the majority of parents become concerned by their children's second birthday. In addition, early concern was not predicted by autism-specific symptomatology, as auditory deficits and low adaptive functioning were the only variables that predicted concern before 18 months.

Socioeconomic Status and Ethnicity. An experiment was designed to examine the influence of ethnicity and socioeconomic status on clinicians' perceptions of children with psychological disorders (Cuccaro, Wright, Rownd, Abramson, Waller & Fender, 1996). One hundred and eighty-five professionals (24% males and 76% females), including speech and language pathologists, school psychologists and child psychiatrists, read two fictional vignettes that described children with either Autistic Disorder or Attention-Deficit Hyperactivity Disorder (ADHD). Furthermore, children were described as either Caucasian or African American, of low or high socioeconomic status (SES), yielding 8 conditions in total. Participants were asked to rate which disorder that they thought described the children in the vignettes from a list of 8 possible disorders. Clinicians who read the description of the child with Autistic Disorder rated Autistic Disorder as the most likely disorder, and clinicians who read the description of the child with ADHD rated ADHD as the most likely disorder that the child had in the vignette. Although ethnicity was not found to be significant in any of the analyses, SES was found to be significant for Autistic Disorder. That is, clinicians who read high SES vignettes were more likely to rate the child with Autistic Disorder or Learning Disorder and clinicians who read low SES vignettes were more likely to rate the child with "cultural deprivation." Moreover, responses differed based on participants' discipline. For example, child psychiatrists were more likely to rate children with Autistic Disorder or

Learning Disorder. The authors concluded that clinicians seemed more likely to consider autism in children who are of high SES and cultural deprivation in children who are of low SES. Although ethnicity did not seem to influence clinicians' perceptions of children with psychological disorders, the authors concluded that additional research is needed to examine the influence of ethnicity and SES in actual clinical settings.

Research was conducted on the relationship between ethnicity and age at diagnosis in a sample of Medicaid-eligible children with autism who received mental health services in Pennsylvania in 1999 (N=406; 79% males, 21% females) (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Children were 9.1 years of age on average at the time of the research, with birthdates ranging from 1989 and 1993. Approximately 60% of the sample were African American, 29% were Caucasian, 8% were Latino and 3% were other ethnicities. Mandell et al. (2002) found that on average, Caucasian children were diagnosed at 6.3 years of age, Latino children at 7.4 years of age, and African American children at 7.9 years of age. On average, Caucasian children entered the autism diagnostic systems at younger ages (6.0 years) compared to Latino (6.5 years) and African American children (7.1 years). In addition, Caucasian children required approximately 4 visits to a professional before diagnosis, Latino children required approximately 8, and African American children required approximately 13 visits to a professional before diagnosis. As a result of their findings, Mandell et al. (2002) stated that possible reasons for the later age of diagnosis in African American and Latino children may include pediatricians failing to take parents' concerns seriously, failing to make referrals and children not receiving consistent medical care.

Research in India was conducted on the clinical presentation of 46 children with Pervasive Developmental Disorders (76% males and 24% females) between ages 2 and 12 who were assessed at the Postgraduate Institute of Medical Education and Research (Malhotra, Chakrabarti, Gupta, Kumar & Gill, 2003). As part of the assessments, detailed developmental histories were obtained from parents. Children completed a series of psychological tests and were diagnosed by a team of professionals as meeting criteria for Autistic Disorder, other Pervasive Developmental Disorders or Childhood Disintegrative Disorder. Within the entire sample, Autistic Disorder was found to be significantly more common in children of high socioeconomic status. For children with Autistic Disorder, age of initial concern was reported to be 10.9 months on average, ranging from 0 to 36 months. As the average age of intake in the sample was 5 years of age, there were considerable delays between the time at which parents became concerned about their children's development and the age at which children were admitted to the clinic. According to the authors, Autistic Disorder was more common in children of high SES, and this finding was likely due to greater accessibility of hospital services for high SES families. In addition, the authors concluded that the help-seeking delay could likely be explained by a lack of awareness of available services and difficulty accessing those services.

Several conclusions can be made regarding literature pertaining to parents' initial concerns and their subsequent experiences obtaining professional help. The majority of parents become concerned about their children's development before their child's third birthday (e.g., Volkmar, Stier & Cohen, 1985; Short & Schopler, 1988, De Giacomo & Fombonne, 1988). Child variables seem to influence the age at which parents initially become concerned. That is, parents of females become concerned earlier than parents of males (e.g., Short & Schopler, 1988; De Giacomo & Fombonne, 1988), parents of children with older siblings may become concerned earlier than parents of only children or children with younger siblings (e.g., De Giacomo & Fombonne, 1988). Also, initial concerns are typically for communication, socialization, abnormal behaviours or medical problems (e.g., Ohta, Nagai, Hara & Sasaki, 1987; De Giacomo & Fombonne, 1988). Although there is a delay between the age at which parents initially become concerned about their child's development and the age at which professional help is sought, relatively little is known about potential child variables that are related to this delay.

Once parents voice their concerns about their children's development, professionals often tell parents to wait for improvement, or refer them on to another professional (e.g., Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997). Researchers have found that children are being diagnosed younger over time, as the average age of diagnosis is approximately 3 ½ years of age for children below age 10, and over 7 years of age for children above age 10 (e.g., Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997). There is some evidence to suggest that Caucasian children are diagnosed earlier than African American and Latino children; however, additional research is need to replicate this finding (Mandell, Listerud, Levy & Pinto-Martin, 2002). Additional research is also needed to reveal potential child variables that may influence the age at which children are diagnosed.

Help-seeking

The literature review indicates that after parents become concerned about their children's development, they tend to wait several months before seeking professional consultation (e.g., Howlin & Moore, 1997). Potential reasons for this delay are currently unknown, as there are no published studies that have examined barriers to help-seeking for parents of children with autism. As there are no parent help-seeking studies directly relevant to the present study, the literature review will be broadened to consider parent help-seeking in other contexts; namely, help-seeking related to children's behaviour problems.

Based on an examination of 47 articles published between 1992 and 2001, Zwaanswijk, Verhaak, Bensing, van der Ende and Verhulst (2003) offered several conclusions on the help-seeking behaviours of parents for their children's general behaviour problems. First, parents are more likely to recognize the need for help when their children's behaviours are sufficiently severe and when several maladaptive behaviours occur together. Second, in comparison to parents with younger or only children, parents with older children are slightly less likely to believe their children's behaviours are problematic, but they are not less likely to seek help. Third, although research has found that non-Caucasian parents are less likely to seek help, this relationship can be explained by SES. There appears to be a relationship between help-seeking and SES only in countries where health care is not available for all citizens, such as in the U.S.A. Fourth, many children are not identified by their physicians; however, identification by physicians is more likely for males than females.

Research on perceived barriers to help-seeking was conducted in a sample of mothers of 272 preschoolers (57.4% males and 42.6% females) in New Zealand (Pavuluri, Luk & McGee, 1996). Parents completed questionnaires that assessed demographics, their children's behaviour problems and their help-seeking behaviours.

Approximately 19% of mothers indicated that they had sought help for their children's behaviour problems, and those who sought help tended to do so through informal sources. Approximately 12% of parents who sought help reported experiencing barriers, including the belief that the problem would alleviate without help (79%) and the belief that they could manage the problem without professional help (59%). Also, parents frequently mentioned that they did not know where to obtain help (38%), they did not believe professional help would alleviate their children's problem (35%), and they thought their children were either too old or too young for professional help (32%). Pavuluri et al. (1996) concluded that community awareness of behavioural disorders should be increased, and that parents' beliefs and attitudes towards help-seeking should be altered to decrease the stigma associated with seeking mental health services for their children. Furthermore, connections should be formed between informal resources and professionals to bridge the gap between informal and formal sources of help.

Birth Order. Longitudinal research was conducted on the relationship between birth order and help-seeking in a sample of children who resided in New Zealand (Feehan, Stanton, McGee & Silva, 1994). Children were born between 1972 and 1973 and the research focused on follow-up assessments of children who were between 9 and 15 years of age. At these assessments, parents were asked about their help-seeking behaviours and children were administered the *Diagnostic Interview Schedule for Children, Child Version* (*DISC-C*; Costello, Edelbrock, Kalas, Kessler & Klarie, 1982). Approximately 36% of parents indicated that they had sought help for their children's behaviour or emotional problems, and parents of males sought help significantly more than parents of females. Females, first-born children and children from small families were significantly more likely to have internalizing disorders than males, later-born children and children from large families. There was no relationship between birth order and help-seeking. The authors concluded that their research did not support an association between help-seeking and birth order, and the relationship between help-seeking and gender was expected, given the higher percentage of externalizing disorders in adolescent males.

Ethnicity. McMiller and Weisz (1996) investigated the relationship between help-seeking and ethnicity in a sample of parents of 192 children who were referred to outpatient clinics in California. Participants (123 males and 69 females) ranged from 7 to 17 years of age and included Caucasian (63%), African American (18%), and Latino (20%) children. Parents were administered a structured interview to obtain information about help-seeking, events leading up to intake and the nature of their children's difficulties. The researchers found that Caucasian parents (53%) first sought help from professionals significantly more often than African American (32%) or Latino parents (30%). African American and Latino parents tended to first seek help from informal sources, such as friends, family and clergy before seeking professional help. Furthermore, before referral to outpatient clinics, the majority of help-seeking attempts for Caucasian parents were directed to professionals and for African American or Latino parents, the majority of help-seeking attempts were directed to informal sources. There was a significant relationship between ethnicity and perceived severity. The correlation between severity and help-seeking from professionals was higher in Latino parents ($r = .43$) and African American parents ($r = .18$) than in Caucasian parents ($r = 1.5$). Thus, the authors concluded that Caucasian parents may be more likely to seek help from professionals first because professional consultations may be more routine in this population. To the extent that African American and Latino parents are underserviced populations, help-seeking from professionals seems to involve overcoming barriers when the nature of their children's difficulties are perceived to be severe.

Utilizing data from the National Institute for Mental Health (NIMH) Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) study, Flisher et al. (1997) investigated variables related to unmet need for mental health services. The sample was comprised of 1,285 children (604 males and 681 females) between ages 9 and 17 who resided in four U.S. states and Puerto Rico. Children were administered the *Diagnostic Interview for Children Version* (*DISC-C*; Costello, Edelbrock, Kalas, Kessler & Klarie, 1982). Approximately 17% of the sample needed services, but did not receive services (unmet need) and 4% of the sample needed, and received services (met need). African American children were significantly more likely than Caucasian children to have unmet needs, however, Latino children were equally as likely as Caucasian children to have an unmet need. After adjusting for gender, age, ethnicity and location, unmet need was found to be related to low SES, the presence of parental psychopathology and poor academic performance.

Variables related to the identification of symptoms of Attention Deficit Hyperactive Disorder (ADHD) and subsequent help-seeking from professionals were investigated in a sample of 389 elementary school students who had, or were suspected of having, ADHD based on their scores on the *Swanson-Nolan-and-Pelham-IV (SNAP-IV)* (Bussing, Zima, Gary & Garvan, 2003). In comparison to females and African American children, males and Caucasian children were significantly more likely to have been identified by parents and evaluated, diagnosed or treated for ADHD. On average, parents reported experiencing 4.1 barriers to obtaining professional help for their children, including uncertainty about where to obtain help, the belief that the problem would alleviate without help, and the belief that symptoms were not severe enough to warrant treatment. Furthermore, in comparison to parents of males, parents of females indicated that they were concerned about the stigma associated with seeking help. In comparison to Caucasian parents, African American parents indicated that they had negative expectations about seeking help. The authors indicated that further research is needed to identify variables related to identification of ADHD symptoms and barriers to seeking professional help.

In summary, several conclusions can be made regarding parents' seeking help for their children's general behavioural problems. First, parents tend to first seek help through informal sources, such as friends and family, before seeking help from professionals (Pavuluri, Luk & McGee, 1996). However, this finding may be influenced by ethnicity, as Caucasian parents have been found to seek help from professionals first and non-Caucasian parents have been found to seek help from informal sources first (McMiller & Weisz, 1996). Finally, it is common for parents to encounter barriers that interfere with the help-seeking process (Bussing, Zima, Gary & Garvan, 2003).

Methodological Issues and Limitations in Past Research

Research on parents' experiences during the course of obtaining an autism diagnosis for their children has occurred in the United Kingdom (e.g., Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997; De Giacomo & Fombonne, 1998), France (Baghdadi, Picot, Pascal, Pry & Aussilloux, 2003), Japan (Ohta, Nagai, Hara & Sasaki, 1987), India (Malhotra, Chakrabarti, Gupta, Kumar & Gill, 2003) and in the U.S.A (Short & Schopler, 1988; Volkmar, Stier & Cohen, 1985; Rogers & DiLalla, 1990; Mandell, Listerud, Levy & Pinto-Martin, 2002). To the extent that there are regional differences in health care services, the availability of professionals and autism awareness, results of previous research may not generalize to another country, such as Canada. On the contrary, it is also important to see how Canada's services for children with autism "measure up" to that of other countries. Thus, research is needed to uncover areas of both strength and weakness in the autism diagnostic system in Canada.

Previous researchers in this area have exposed several commonalities in parents' initial concerns and process of obtaining professional help. For example, researchers have identified that there is a delay between the age at which parents initially become concerned about their children's development and the age at which children are diagnosed with autism. Yet, relatively little is known about potential child variables that may be related to this delay, such as gender, ethnicity, birth order and socioeconomic status. Understanding the influence of child variables on the age at initial concern and the age at diagnosis would have direct implications for improving methods of autism identification in home environment and in health care settings.

Purpose of the Current Research

Justification and Rationale of Current Study

The present research will investigate parents' experiences during the course of obtaining a diagnosis for their children throughout Ontario. Ontario is Canada's second largest province, with a population of 11,410,045 people according to 2001 Census Data (Statistics Canada, 2003). The average family income ($73,849) is higher than the national average family income ($66,160). Residents who are Canadian Citizens or landed immigrants are entitled to the Ontario Health Insurance Plan (OHIP), which is health insurance funded by the government of Ontario (Ministry of Health and Long Term Care, 2002).

Additionally, the present research will test the generalizability of past findings from the U.K., France, India and the U.S.A, while accumulating potentially relevant original information about the autism diagnostic system in a Canadian province. The age at which parents initially become concerned about their children's development will be examined and, in order to extend past research, the relationship between age at initial concern will be examined with respect to several child variables (i.e., gender, ethnicity, birth order and socioeconomic status). Previous research has shown that parents tend to wait 5-6 months before seeking help from health care professionals (e.g., Howlin & Moore, 1997); however, reasons for this delay have not been explicitly explored. In the present research, help-seeking behaviours of parents of children with autism will be examined because relatively little is known about this area. That is, little is known about the informal sources through which parents do seek help and the systematic barriers that they are encountering.

The present research will also examine professionals' responses to parents' concerns in order to obtain a rough estimate of the region's sophistication in autism diagnostic services. Although past researchers have found that the average age of diagnosis is decreasing over time, the average age of diagnosis is still relatively high, given the importance of early identification. The present research will extend the previous studies by examining the influence of child variables (i.e., gender, ethnicity, birth order and socioeconomic status) on the age at diagnosis. If child variables are related to the age at diagnosis, then improved methods of detection may be needed for children who are underserviced.

Hypotheses

Hypothesis I. Demographic variables and age at initial concern

1a: Gender. It is predicted that parents of females will be concerned earlier than will parents of males (e.g., Short & Schopler, 1988; De Giacomo & Fombonne, 1998).

1b: Birth order. It is anticipated that parents of youngest children will be concerned about their children's development earlier than will parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1988).

Exploratory Concerns. Ethnicity and socioeconomic status and their impact on age at initial concern will be explored. Due to the lack of previous research in these areas, no explicit hypotheses will be formulated.

Hypothesis II. Initial help-seeking efforts by parents

It is predicted that the majority of parents will first seek help through informal sources, such as friends and family, before seeking help from formal sources, such as physicians or psychologists (e.g., Pavuluri, Luk & McGee, 1996; McMiller & Weisz, 1996).

Hypothesis III. Demographic variables and help-seeking

3a: Gender. It is predicted that parents with female children will seek help earlier than will parents of male children, as females with autism typically have more severe cognitive and adaptive deficits (e.g., Volkmar, Szatmari & Sparrow, 1993).

3b: Ethnicity. It is expected that non-Caucasian children will experience longer delays than will Caucasian children before receiving professional help (e.g., Flisher et al., 1997; Bussing, Zima, Gary & Garvan, 2003).

3c: Birth order. It is anticipated that parents of youngest children will seek help earlier than will parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1998).

3d: Socioeconomic status. To the extent that health care resources are more accessible to individuals of high SES, it was predicted that the help-seeking delay would be shorter for children in the high SES group compared to children in the low SES group (e.g., De Giacomo & Fombonne, 1998).

Hypothesis IV. Barriers to professional help-seeking

No published study has explicitly addressed parent-identified barriers to professionals help-seeking for young children with autism. It is predicted that parents of children with autism will believe that doctors will not take their concerns seriously, or practicality issues, such as transportation or lack of available child care, will be identified by parents as barriers to seeking help.

Hypothesis V. Demographic variables and age at diagnosis

5a: Gender. As previous research has found that females with autism typically experience greater cognitive and adaptive deficits (e.g., Volkmar, Szatmari & Sparrow, 1993), it is hypothesized that females will be diagnosed earlier than males.

5b: Ethnicity. It is predicted that non-Caucasian children with be diagnosed later than will Caucasian children, as the former group are thought to be underserviced with respect to health care services (Mandell, Listerud, Levy & Pinto-Martin, 2002).

5c: Birth Order. As parents of youngest children are expected to seek help sooner than parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1998), it is similarly expected that youngest children will be diagnosed earlier than middle and oldest children.

5d: Socioeconomic status. It is expected that children in low SES families will be diagnosed later than will children in high SES families, as the former group are thought to be underserviced with respect to health care services (e.g., Flisher et al., 1997).

Chapter II

METHOD

Participants

Participant Numbers and Characteristics

Respondents. Questionnaires were completed by 82 parents. Because the research was primarily concerned with investigating the experiences of parents of children with autism, participants had to be either the biological or adoptive parent or the legal guardian of a child with an ASD. One parent who completed a questionnaire had a child who had not yet been diagnosed with an autism spectrum disorder and this participant was excluded from all analyses due to the lack of a formal diagnosis. Two additional children were excluded from analyses because they were born prior to 1980, and thus would have been diagnosed according to DSM-II diagnostic criteria. The diagnostic criteria for autism spectrum disorders changed considerably with the publication of the DSM-III in 1980, so children diagnosed according to DSM-II criteria were excluded to obtain a more homogeneous sample. The resulting sample consisted of 79 parents who completed 81 questionnaires (two parents had two children with an autism spectrum disorder and completed a separate questionnaire for each child).

The majority of participants (95%) were mothers (92.4% biological, 1.3% adoptive and 1.3% step-mothers). Fathers (5.1%) also completed questionnaires, including biological (3.8%) and adoptive fathers (1.3%). The average age of parents who participated was 39.93 years of age (*SD* = 6.16; ranging from 28 to 58 years of age). The majority of participants were Caucasian (91.1%), followed by Hispanic (3.8%) and Asian/Pacific Islander (2.5%) and Arabic/Middle Eastern (2.5%). Parents who participated in the research were born in Canada (81%), the U.S.A (5.1%) and other countries (14.3%), including El Salvador, England, Fiji Islands, India, Germany, Italy, Scotland, Switzerland, Venezuela, Lebanon, Vietnam and Chile. Participants reported that their child's other parent was born in Canada (74.7%), the U.S.A (1.3%) and other countries (24%), including Germany, France, England, El Salvador, the Philippines, Yugoslavia, India, Northern Ireland, Lebanon, Libya and Vietnam. The majority of participants indicated that their first language was English (89.9%), followed by Spanish (2.5%), German (2.5%), French, (1.3%), Arabic (1.3%), Vietnamese (1.3%) and Punjabi (1.3%). Participants resided throughout Ontario in the Southwest (50%), Eastern (6.4%), Central (21.8%) and Northern (21.8%) regions of the province. Area of residence was not provided by one participant.

At the time of questionnaire completion, 86.1% of participants were married, 10.2% were separated or divorced, 1.3% were engaged, 1.3% were single and 1.3% were widowed. The highest level of education attained by participants included High School (13.9%), some College or University (21.5%), College or University degree (55.7%) and Post-Graduate school (8.9%). According to the Hollingshead (1975) criteria for measuring socioeconomic status, 1.4% were unskilled labourers and menial service workers, 11.3% were machine workers and semiskilled workers, 35.2% were skilled craftsmen and clerical, sales workers, 36.6% were medium business and minor professionals, technical, and 15.5% were major business and professionals. SES was not calculated for 8 families due to missing data. Parents of higher SES appear to be over-represented in the current sample compared to the national average. However, this would be expected given that the sample was drawn from a population of parents who were members of an organization (i.e., the Autism Society of Ontario) that requires annual membership fees (e.g., Wing, 1980).

Children. Questionnaires were completed for 81 children (70 males and 11 females). The male-female ratio of 6.36:1 is in accordance with the expected male-female prevalence ratio for ASD (APA, 2000). According to parent report, 52 children had Autism, 6 children had Asperger's Disorder and 23 children had PDD-NOS. The sample was predominately Caucasian (89.9%), followed by Arabic/Middle Eastern (2.5%), Asian/Pacific Islander (2.5%), Native Canadian (1.2%), Hispanic (1.2%) and mixed ethnicities (2.5%). Seventy-seven children were born in Canada, 3 children were born in the U.S.A and 1 child was born in France. The majority of the children spoke English first in the home (93.8%), however; in 6.1% of cases, Spanish, French, Arabic and Vietnamese were spoken first in the home. Regarding birth order, 36 children were the youngest in the family, 17 were in the middle, 23 were the oldest children in the family and there were 5 "only" children.

Recruitment Methods

The present research was reviewed and approved by the University of Windsor's Research Ethics Board. The researcher attended several social functions in which parents of children with autism were present, including a parent meeting for children with high-functioning autism, the annual general meeting of Autism Society of Ontario, Windsor-Essex County Chapter and the annual general meeting for the provincial Autism Society of Ontario. Three participants indicated that they preferred to complete a telephone interview instead of completing the questionnaire, and interviews were conducted by the researcher. Second, the researcher sent 10 to 15 questionnaires and recruitment flyers each to 13 different Chapters of the Autism Society of Ontario (See Appendix A) to be forwarded to parents in the region. Third, questionnaires were sent to parents of children who were on the waiting list or currently receiving treatment at the Summit Centre Preschool for Treatment of Children with Autism. The Summit Centre is a Southwest Regional Autism Program for Preschoolers (SWRAPP) provider that offers intensive early intervention for children who live within one hour of Windsor, Ontario (Summit Centre, 2004).

In order to raise awareness about the research, flyers (See Appendix A) were posted in Windsor at several locations that are frequented by parents, including churches and libraries. As previously explained, flyers were sent to different Chapters of the Autism Society of Ontario, along with research questionnaires. Additionally, the recruitment flyer was posted on-line on the News Bulletin for the Ontario Adult with Autism Research and Support Network.

The response rate of 30.7% was calculated by dividing the number of questionnaires completed and returned (82) by the total number of questionnaires distributed (267). In order to increase sample size, it was necessary to "network" with parents by providing them with extra questionnaires to give to other parents of children with autism with whom they were in contact. Thus, the total number of questionnaires distributed included questionnaires that were given directly to parents, as well as extra questionnaires that were offered to be given to other parents of children with autism.

Measures

Diagnostic Experiences Questionnaire

The questionnaire was designed for the present research and is included in Appendix B. Demographic information was collected for children of parents who participated in the research. Information requested included child's date of birth, gender, first language, ethnicity and diagnosis. Next, questions were asked about parents' initial concerns about their children's development, barriers to seeking help, where they sought help, professionals' responses to their concerns and the outcome of help-seeking. Finally, demographic information was collected for parents on their date of birth, gender, first language, ethnicity, marital status, education and employment status.

Procedures

Participants who were recruited at the annual general meetings for the Autism Society of Ontario were provided with a stamped, addressed envelope that included the letter of information and the research questionnaire. As an incentive for participation, participants were provided with a form to include their contact information to enter a draw for $100. The letter of information (see Appendix C) described the purpose of the study as "an investigation of parents' experiences obtaining an autism diagnosis for their child." Participants were informed of their rights as research participants and provided with a phone number for the researcher and the research supervisor if they had questions about the research. In order to ensure anonymity and confidentiality, participants were instructed not to include their name on the questionnaire. Participants chose to either complete the questionnaires at the meetings, or complete the questionnaire at a later date and mail the returned questionnaire to the researcher. Participants who were recruited at a parent group for high functioning children with autism provided the researcher with their contact information for a telephone interview that was conducted by the researcher. The researcher began by reading the letter of information and after verbal consent was obtained, the researcher proceeded to ask participants the questions on the research questionnaire. Finally, the researcher explained the draw for $100 and participants were given the option of including their name in the draw.

Participants were also recruited through a mail-out procedure. First, the researcher sent a package of materials to ten Chapters of the Autism Society of Ontario with mailing addresses that were available on Chapter websites. A letter requesting the Chapter to forward the questionnaires to parents in their region was also included (See Appendix D), along with ten stamped, addressed envelopes that each contained the letter of information, the questionnaire and a form to include their contact information to enter a draw for $100. Through subsequent follow-up with Chapter presidents and staff, seven Chapters indicated that they would forward the questionnaires to parents in their region.

The researcher subsequently attempted to contact all Chapters of the Autism Society of Ontario that were not included in the mail-out by telephone and e-mail. From such attempts, an additional three Chapters indicated that they were willing to forward questionnaires to parents in their region. One Chapter indicated that they would forward questionnaires to parents at a later date. For this Chapter, participants were given the option of being included in a draw for one of four prizes of $25 each because the draw for $100 would have passed by the time the questionnaires would be received.

For parents of children who were on the waiting list at the Summit Centre Preschool for Treatment of Children with Autism, questionnaire packages were sent by mail and for parents of children who were currently receiving treatment, questionnaire packages were left in parents' mailboxes at the treatment facility. Because the date for the draw for $100 had passed, parents in this recruitment group were given the option of including their name in a draw for one of four prizes of $25 each. Names for the prizes were randomly drawn and cheques were sent in the mail to those selected.

Chapter III

RESULTS

The results of the research are included in several sections, and information included in each section will be explained for clarity. First, descriptive statistics conducted utilizing data from the entire sample are presented for several variables, including date of birth, the first person to be concerned about children's development, age at initial concern, areas of concern, the help-seeking delay, age at first, second and third appointments, professionals seen at each appointment, professionals' responses to parents' concerns, age at diagnosis, year of diagnosis and socioeconomic status (SES). Next, data screening is explained. In the following sections, correlational analyses and analyses conducted to investigate the research hypotheses are presented, with outliers eliminated. Correlational analyses were conducted for continuous variables (i.e., date of birth, age at initial concern, help-seeking delay, age at first, second and third appointment, age at diagnosis, year of diagnosis, and SES). Results of analyses investigating the research hypotheses are then discussed in turn. Finally, exploratory analyses are presented that were conducted on parents' opinions about how to improve the autism diagnostic system, as well as on variables that predicted age at diagnosis. For all analyses, the statistical significance level was set to .05.

Descriptive Statistics

Date of Birth

Children who participated in the research were born between 1984 and 2001 (*M* = 1995.17, *SD* = 4.42). Sixteen percent of the children were born between 1984 and 1990, approximately 36% were born between 1991 and 1995 and approximately 48%

were born between 1996 and 2001. Table 1 provides the distribution of children's birth years in approximately half-decade intervals by diagnostic group. A comparison of group differences in birth year indicated that children with Autistic Disorder ($M = 1996.00$, $SD = 4.18$) were born later than children with Asperger's Disorder ($M = 1991.41$, $SD = 4.54$), $t(56) = -2.54$, $p = .01$. No differences in date of birth were found between children with Autistic Disorder ($M = 1996.00$, $SD = 4.18$) and PDD-NOS ($M = 1994.24$, $SD = 4.43$), $t(73) = -1.66$, $p > .05$, or between children with Asperger's Disorder ($M = 1991.41$, $SD = 4.54$) and PDD-NOS ($M = 1994.24$, $SD = 4.43$), $t(27) = 1.39$, $p > .05$.

The First Person to be Concerned About Children's Development

The majority of parents who completed the questionnaires (62.50%) indicated that they were the first person to become concerned about their children's development. Parents reported that an extended family member (7.50%), their child's day care staff or teacher (6.25%), their child's doctor (2.50%), another health care practitioner (2.50%), a friend (1.25%), or their spouse (2.50%) was the first person to be concerned about their child's development. In one case (1.25%), a step-parent indicated that the child's biological mother was the first person to be concerned about the child's development. Parents reported that they were concerned about their children's development at the same time as their spouse (11.25%), their child's day care staff or teacher (1.25%), or family member (1.25%). When looking at the data overall, biological mothers were the first ones to become concerned (either alone, or at the same time as another person) about their children's development in 75% of cases.

Table 1

Frequency Data for Children's Birth Years by Diagnostic Group

Diagnosis	Years		
	1984-1990	1991-1995	1996-2001
Autistic Disorder (*N* = 52)	6	16	30
PDD-NOS (*N* = 23)	4	11	8
Asperger's Disorder (*N* = 6)	3	2	1
Total	13	29	39

Age at Initial Concern

Parents were asked to indicate the age of their children when they initially became concerned about their development. Fifty-seven percent of parents reported that their initial concern was in one area of development and 43% of parents reported that their initial concern was in more than one area. The most common initial concerns were about abnormal behaviours (30.2%), language development (27.8%), social skills (27.0%) and medical problems or delays in milestones (15.1%). Figure 1 provides the percentage of parents' initial concerns in each developmental area.

The average age at initial concern was 19.71 months (*SD* = 13.53), ranging from 1 month to 84 months of age. More than half of parents (57.33%) were concerned by 18 months of age, while 80% of all parents were concerned by 24 months of age (See Table 2). Table 3 provides the distribution of age at initial concern according to diagnostic group. On average, parents of children with Autistic Disorder were concerned about their development at 18.35 months of age (*SD* = 11.51), parents of children with PDD-NOS were concerned on average by 21.70 months of age (*SD* = 16.43) and parents of children with Asperger's Disorder were concerned by 24.17 months of age (*SD* = 18.72). There were no significant differences in age at initial concern between children with Autistic Disorder and children with Asperger's Disorder, $t(53) = -1.09, p > .05$, and PDD-NOS, $t(67) = -.97, p > .05$, nor were significant differences found between children with Asperger's Disorder and children with PDD-NOS , $t(24) = .31, p > .05$.

Areas of Concern

Parents were asked to indicate the age at which they became concerned about their children's language development, social skills, the presence of abnormal behaviours

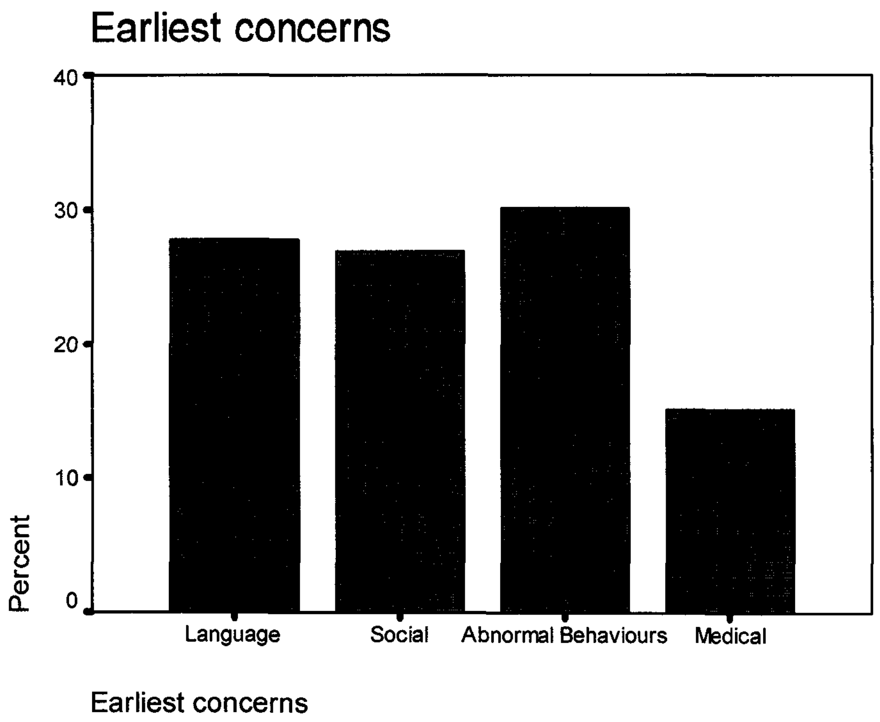

Figure 1. Percentage of parents' initial concerns in each developmental area.

Table 2

Child's Age in Months When Parents Initially Became Concerned

Age in months	*N*	%	Cumulative %
0 – 6	12	16.00	16.00
7 – 12	13	17.33	33.33
13 – 18	18	24.00	57.33
19 – 24	17	22.67	80.00
25 – 30	6	8.00	88.00
31 – 36	4	5.30	93.30
37 – 84	5	6.67	100.00

Note. $N = 75$

Table 3

Descriptive Statistics for Age in Months at Initial Concern by Diagnostic Group

Diagnosis	*M*	*SD*	Range
Autistic Disorder (*N* = 49)	18.35	11.51	1 - 48
PDD-NOS (*N* = 20)	21.70	16.43	6 - 84
Asperger's Disorder (*N* = 6)	24.17	18.72	1 - 48
Total (*N* = 75)	19.71	13.53	1 - 84

or medical problems or delays in milestones. On average, parents were concerned about medical problems or delays in milestones at 22.06 months of age (*SD* = 21.27), followed by language development at 22.10 months (*SD* = 8.62), abnormal behaviours at 22.29 months (*SD* = 14.03) and social skills at 24.97 months of age (*SD* = 17.36). Means and standard deviations for areas of initial concern in each developmental area are provided in Table 4 by diagnostic group. A 3 x 4 ANOVA was conducted between diagnostic group (Autistic Disorder vs. Asperger's Disorder vs. PDD-NOS) and age at initial concern in each area (language vs. social vs. abnormal behaviours vs. medical problems). Significant between-groups differences were found between children with Autistic Disorder and children with PDD-NOS for social skills, $F(2, 66) = 3.23, p < .05$. Specifically, parents were concerned earlier about social skills for children with Autistic Disorder ($M = 21.64$, $SD = 10.10$) compared to children with PDD-NOS ($M = 33.56$, $SD = 27.03$). There were no differences between groups for language, $F(2, 66) = .73, p > .05$, abnormal behaviours, $F(2, 69) = 2.11, p > .05$, or medical concerns, $F(2, 33) = 1.90$, $p > .05$.

Help-seeking Delay

The help-seeking delay for each child was calculated by subtracting the age of the child at the first appointment after parents' became concerned about their development from the age at which parents initially became concerned about their children's development. For three participants, the help-seeking delay was less than zero and these cases were excluded from these analyses because it was apparent that parents did not interpret the question correctly (i.e., the smallest delay would be zero months if parents took their children to a doctor immediately after they became concerned about

Table 4

Descriptive Statistics for Areas of Initial Concern by Diagnostic Group

Diagnosis	*M*	*SD*	Range	*N*
Autistic Disorder (*N* = 52)				
Language	22.06	8.49	6 - 48	47
Social Skills	21.64	10.10	6 - 48	45
Abnormal Behaviours	19.93	11.33	1 - 54	46
Medical/Delays	16.86	13.39	1 - 48	21
PDD-NOS (*N* = 23)				
Language	22.74	9.08	10 - 42	19
Social Skills	33.56	27.03	9 - 120	18
Abnormal Behaviours	25.95	18.90	8 - 96	19
Medical/Delays	29.50	29.72	6 - 96	12
Asperger's Disorder (*N* = 6)				
Language	12.00	-	-	1
Social Skills	24.17	18.72	1 - 48	6
Abnormal Behaviours	30.00	12.00	18 - 48	5
Medical/Delays	42.00	-	-	1

Table 4 (continued)

Diagnosis	*M*	*SD*	Range	*N*
Total (*N* = 81)				
Language	22.10	8.62	6 - 48	67
Social Skills	24.97	17.36	1 - 120	69
Abnormal Behaviours	22.29	14.03	1 - 96	70
Medical/Delays	22.06	21.27	1 - 96	34

Note. Missing values are represented by the – symbol.

their development). The average help-seeking delay was 10.38 months (*SD* = 16.95) and the delay ranged from zero months to 127 months of age. Table 5 provides the descriptive statistics for help-seeking delay by diagnostic group. After parents became concerned about their children's development, there was an average waiting period of 7.56 months (*SD* = 6.67) before their first appointment with a professional for children with Autistic Disorder, 37.00 months (*SD* = 45.50) for children with Asperger's Disorder and 8.37 months (*SD* = 11.43) for children with PDD-NOS. Analyses to examine between group differences were conducted and the assumption of homogeneity of variance was not met. Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. There were no significant differences in the help-seeking delay between children with Autistic Disorder and Asperger's Disorder, $t(5.03) = -1.58, p > .05$, and children with PDD-NOS, $t(23.59) = .77, p > .05$, nor were there significant differences between children with Asperger's Disorder and PDD-NOS $t(5.20) = 1.53, p > .05$.

Age At First, Second and Third Appointments

Parents were asked to indicate how old their children were at the first, second and third appointments with professionals after they became concerned about their children's development. For the entire sample, children were approximately 29 months of age at the first appointment. The second appointment occurred approximately 7 ½ months later. At the third appointment, children were approximately 44 months of age (approximately 7 ½ months after the second appointment). Table 6 provides the descriptive statistics for ages

Table 5

Descriptive Statistics for the Help-seeking Delay

Diagnosis	*M*	*SD*	Range
Autistic Disorder (*N* = 43)	7.56	6.67	0 - 26
PDD-NOS (*N* = 19)	8.37	11.43	0 - 35
Asperger's Disorder (*N* = 6)	37.00	45.50	12 - 127
Total (*N* = 68)	10.38	16.95	0 - 27

Note. Values represent months.

Table 6

Children's Age in Months at First, Second and Third Appointments by Diagnostic Group

Diagnosis	*M*	*SD*	Range	*N*
Autistic Disorder				
First	24.75	10.88	3 - 51	48
Second	29.32	29.32	3 - 66	41
Third	36.30	36.30	4 - 78	33
PDD-NOS				
First	30.00	21.53	8 - 108	21
Second	40.17	31.27	10 - 132	18
Third	45.53	34.89	12 - 132	15
Asperger's Disorder				
First	61.17	36.08	36 - 133	6
Second	73.17	34.38	48 - 133	6
Third	86.20	33.54	57 - 134	5
Total				
First	29.13	19.60	3 - 133	75
Second	36.37	24.79	3 - 133	65
Third	43.62	27.92	4 - 134	53

at each appointment according to diagnostic group. There were no differences in age at first appointment between children with Autistic Disorder (*M* = 24.75, *SD* = 10.88) and PDD-NOS (*M* = 30.00, *SD* = 21.53), *t*(67) = -1.35, *p* > .05. Additional *t*-tests were conducted between children with Autistic Disorder and children with Asperger's Disorder and between children with Asperger's Disorder and PDD-NOS and the assumption of homogeneity of variance was not met. Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. The *t*-test was marginally significant, *t*(5.11) = -2.46, *p* = .06 between children with Autistic Disorder (*M* = 24.75, *SD* = 10.88) and Asperger's Disorder (*M* = 61.17, *SD* = 36.08). However, significant differences were found between children with Asperger's Disorder (*M* = 61.17, *SD* = 36.08) and PDD-NOS (*M* = 30.00, *SD* = 21.53), *t*(25) = 2.68, *p* = .01, indicating that children with PDD-NOS were younger at the first appointment to address their parents' concerns than children with Asperger's Disorder. At the time of the second appointment, children with Autistic Disorder were 29.32 (*SD* = 12.63) months of age on average, children with Asperger's Disorder were 73.17 (*SD* = 34.38) months of age and children with PDD-NOS were 40.17 (*SD* = 31.27) months of age. Significant differences were found between children with Asperger's Disorder and children with PDD-NOS, *t*(22) = -2.19, *p* < .05, indicating that children with Asperger's Disorder were significantly older at the time of the second appointment than children with PDD-NOS.

In addition, *t*-tests were conducted between children with Autistic Disorder and children with Asperger's Disorder and between children with Autistic Disorder and PDD-NOS and the assumption of homogeneity of variance was not met (SPSS Inc., 2001).

Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. Children with Autistic Disorder were significantly younger than children with Asperger's Disorder at the time of the second appointment, $t(5.20) = -3.09$, $p < .05$. There were no significant differences in age at the second appointment between children with Autistic Disorder and children with PDD-NOS, $t(19.48) = -1.42$, $p > .05$.

At the time of the third appointment, children with Asperger's Disorder (M = 86.20, SD = 33.54) were significantly older than children with PDD-NOS (M = 45.53, SD = 34.89), $t(18) = 2.28$, $p < .05$. Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. The assumption of homogeneity of variance was not met for *t*-tests between children with Autistic Disorder and children with Asperger's Disorder, and between children with Autistic Disorder and PDD-NOS (SPSS Inc., 2001). Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. Children with Asperger's Disorder (M = 86.20, SD = 33.54) were significantly older than children with Autistic Disorder (M = 36.30, SD = 15.91), $t(4.28) = -3.27$, $p < .05$. There were no significant differences in age at the third appointment between children with Autistic Disorder (M = 36.30, SD = 15.91) and children with PDD-NOS (M = 45.53, SD = 34.89), $t(16.71) = -.98$, $p > .05$.

Professional Seen at First, Second and Third Appointments

For 12 children, there was more than one professional listed for each appointment and these cases were excluded from analyses because it was unclear which professional was actually seen at each appointment. For the entire sample, the majority of children were seen by a general practitioner (40.27%) or a paediatrician (31.94%) at the first appointment after parents became concerned about their children's development. At both the second and third appointments, the majority of children were seen by either a paediatrician (32.31% and 30.77%, respectively) or child psychologist (24.62% and 30.77%, respectively). Other professionals included audiologists, speech and language pathologists, geneticists, neurologist, ear nose and throat specialist or a team of professionals. Table 7 provides a list of professionals and the frequency with which children were seen according to diagnostic group.

Professionals' Responses to Parents' Concerns

At the first appointment after parents became concerned about their children's development, most professionals referred children to another professional (43.37%) or parents were told to "wait and see" if behaviour or development improves (32.53%), while few professionals diagnosed with an autism spectrum disorder (12.05%). At the second appointment, most professionals referred (40.33%) or diagnosed an autism spectrum disorder (24.19%). At the third appointment, most professionals diagnosed with autism spectrum disorder (44.26%) or referred children to another professional (34.43%). The frequency data for professionals' responses to parents' concerns by diagnostic group are provided in Table 8.

Age at Diagnosis

Age at diagnosis ranged from 18 months of age to 180 months, or 15 years age. For the entire sample, the average age of diagnosis was 51.49 (*SD* = 32.85) months, or approximately 4.29 years of age. Table 9 provides the descriptive statistics for ages at

Table 7

Frequency with Which Different Professionals were Consulted at Appointments by Diagnostic Groups

	First		Second		Third	
	N	%	N	%	N	%
Autistic Disorder						
General Practitioner	20	44.44	4	9.76	3	9.7
Paediatrician	14	31.11	13	31.70	7	22.6
Child Psychologist	3	6.67	8	19.51	9	29.0
Psychiatrist	1	2.22	2	4.88	1	3.2
Other	5	11.11	12	29.27	11	35.48
Unknown	2	4.44	2	4.88	0	0.00
Total	45	100.00	41	100.00	31	100.00
PDD-NOS						
General Practitioner	7	33.30	2	11.10	0	0.00
Paediatrician	8	38.1	7	38.90	5	31.25
Child Psychologist	4	19.0	7	38.90	4	25.00
Psychiatrist	0	0.00	1	5.60	2	12.50
Other	1	4.80	1	5.60	5	31.25
Unknown	1	4.80	0	0.00	0	0.00
Total	21	100.00	18	100.00	16	100.00

Table 7 (Continued)

	First		Second		Third	
	N	%	N	%	N	%
Asperger's Disorder						
General Practitioner	2	33.33	1	16.70	0	0.00
Paediatrician	1	16.70	0	0.00	1	20.00
Child Psychologist	3	50.00	1	16.70	3	60.00
Psychiatrist	0	0.00	3	50.00	1	20.00
Other	0	0.00	0	0.00	0	0.00
Unknown	0	0.00	1	16.70	0	0.00
Total	6	100.00	6	100.00	5	100.00
Total						
General Practitioner	29	40.28	7	10.77	3	5.77
Paediatrician	23	31.94	20	30.77	13	25.00
Child Psychologist	10	13.89	16	24.62	16	30.77
Psychiatrist	1	1.39	6	9.23	4	7.69
Other	6	8.33	13	20.00	16	30.77
Unknown	3	4.17	3	4.62	0	0.00
Total	72	100.00	65	100.00	52	100.00

Table 8

Professionals' Responses to Parents' Concerns by Diagnostic Group

	First		Second		Third	
	N	%	N	%	N	%
Autistic Disorder						
Referral	26	49.10	17	40.50	13	37.10
"Wait and see"	18	34.00	8	19.00	2	5.70
Diagnosed with an ASD	5	9.40	12	28.60	19	54.30
"Child is developing normally"	2	3.80	1	2.40	1	2.90
Diagnosed with other disorder	0	0.00	1	2.40	0	0.00
Other	2	3.80	3	7.20	0	0.00
Total	53	100.00	42	100.00	35	100.00
PDD-NOS						
Referral	8	34.80	7	43.80	6	37.50
"Wait and see"	8	34.80	4	25.00	0	0.00
Diagnosed with an ASD	4	17.40	2	12.50	7	43.80
"Child is developing normally"	1	4.30	2	12.50	1	6.30
Diagnosed with other disorder	1	4.30	1	6.30	1	6.30
Other	1	4.30	0	0.00	1	6.30
Total	23	100.00	16	100.00	16	100.00

Table 8 (continued)

	First		Second		Third	
	N	%	N	%	N	%
Asperger's Disorder						
Referral	2	28.60	1	25.00	2	40.00
"Wait and see"	1	14.30	0	0.00	1	20.00
Diagnosed with an ASD	1	14.30	1	25.00	1	20.00
"Child is developing normally"	2	28.60	2	50.00	0	0.00
Diagnosed with other disorder	1	14.30	0	0.00	0	0.00
Other	0	0.00	0	0.00	1	20.00
Total	7	100.00	4	100.00	10	100.00
Total						
Referral	36	43.37	25	40.33	21	34.43
"Wait and see"	27	32.53	12	19.35	3	4.91
Diagnosed with an ASD	10	12.05	15	24.19	27	44.26
"Child is developing normally"	5	6.02	5	8.06	2	3.28
Diagnosed with other disorder	2	2.41	2	3.23	1	1.64
Other	3	3.61	3	4.84	1	1.64
Total	83	100.00	62	100.00	61	100.00

Table 9

Descriptive Statistics for Age in Months at Diagnosis by Diagnostic Group

Diagnosis	*M*	*SD*	Range
Autistic Disorder (*N* = 52)	40.96	19.83	18 - 147
PDD-NOS (*N* = 23)	63.78	43.74	25 - 180
Asperger's Disorder (*N* = 6)	95.67	25.38	73 - 140
Total (*N* = 81)	51.49	32.85	18 - 80

diagnosis by diagnostic group. Children with Asperger's Disorder (*M* = 95.67, *SD* = 25.38) were significantly older than children with Autistic Disorder (*M* = 40.96, *SD* = 19.96) at the time of diagnosis, $t(56) = -6.22, p < .01$. There were no significant differences in age at diagnosis between children with Asperger's Disorder (*M* = 95.67, *SD* = 25.38) and children with PDD-NOS (*M* = 63.78, *SD* = 43.74), $t(27) = 1.70, p > .05$. The assumption of homogeneity of variance was not met for the *t*-tests between children with Autistic Disorder and children with PDD-NOS (SPSS Inc., 2001). Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. There were no significant differences in age at diagnosis between children with Autistic Disorder (*M* = 40.96, *SD* = 19.96) and children with PDD-NOS (*M* = 63.78, *SD* = 43.74), $t(28.09) = -2.40, p > .05$.

Year of Diagnosis

Children were diagnosed between 1987 and 2004. The average year of diagnosis was 1998.89 (*SD* = 4.02), with the year 2000 being the median year of diagnosis. Table 10 provides the frequency data for year of diagnosis according to diagnostic group. There were no differences in average year of diagnosis between children with Autistic Disorder (*M* = 1998.92, *SD* = 4.17) and PDD-NOS (*M* = 1999.00, *SD* = 3.81), $t(73) = -.08, p > .05$, between children with Autistic Disorder (*M* = 1998.92, *SD* = 4.17) and children with Asperger's Disorder (*M* = 1998.17, *SD* = 4.12), $t(56) = -.42, p > .05$, or between children with Asperger's Disorder (*M* = 1998.17, *SD* = 4.12) and PDD-NOS, (*M* = 1999.00, *SD* = 3.81) $t(27) = -.47, p > .05$.

Table 10

Descriptive Statistics for Year of Diagnosis by Diagnostic Group

Diagnosis	*M*	*SD*	Range
Autistic Disorder (*N* = 52)	1998.98	4.17	1987 - 2004
PDD-NOS (*N* = 23)	1999.00	3.81	1992 - 2004
Asperger's Disorder (*N* = 6)	1998.17	4.12	1992 - 2002
Total (*N* = 81)	1998.98	4.02	1987 - 2004

Socioeconomic Status

The Hollingshead Index (1975) provides a method of calculating SES based on level of education and area of employment. For the overall sample, the average Hollingshead score was 41.5 ($SD = 10.91$), with a range between 16.45 and 62.20. There were no differences in SES between children with Autistic Disorder ($M = 40.58$, $SD = 11.20$) and PDD-NOS ($M = 43.08$, $SD = 9.44$), $t(63) = -.86$, $p > .05$, between children with Autistic Disorder ($M = 40.58$, $SD = 11.20$) and children with Asperger's Disorder ($M = 43.86$, $SD = 13.85$), $t(50) = -.66$, $p > .05$, or between children with Asperger's Disorder ($M = 43.86$, $SD = 13.85$) and PDD-NOS, ($M = 43.08$, $SD = 9.44$), $t(23) = -.16$, $p > .05$.

Geographical Location

Children who participated in the research resided throughout Ontario, in the Southwest (50%), Eastern (6.4%), Central (21.8%) and Northern (21.8%) regions of the province. One-way ANOVAs were conducted to examine whether there were regional differences in age at initial concern, the help-seeking delay, and age at diagnosis. Means and standard deviations are provided in Table 11. There were significant regional differences in age at initial concern, $F(3, 72) = 3.13$, $p < .05$ and Tukey's post hoc analyses revealed that parents in the Eastern region of the province ($M = 9.80$, $SD = 7.76$) were concerned about their children's development significantly earlier than parents in all other regions. There were no significant regional differences in the help-seeking delay, $F(3, 65) = .69$, $p > .05$ or in age at diagnosis, $F(3, 77) = 1.47$, $p > .05$. Although not significant, children who lived in the Eastern ($M = 67.20$, $SD = 64.71$) and Northern ($M = 63.41$, $SD = 49.50$) regions were diagnosed later than children who lived in the

Table 11.

Descriptive Statistics for Dependent Variables by Geographical Region

Variable		*M*	*SD*	*N*
Age at Initial Concern n.s.				
	Southwestern	16.94	10.69	36
	Northern	20.40	19.24	15
	Central	26.65	11.83	17
	Eastern	9.80	7.76	5
	Total	19.71	13.53	75
Help-seeking Delay n.s.				
	Southwestern	8.00	9.59	32
	Northern	15.67	31.76	15
	Central	11.13	9.90	15
	Eastern	9.00	7.53	4
	Total	10.38	16.95	68
Age at Diagnosis n.s.				
	Southwestern	46.21	21.53	39
	Northern	63.41	49.50	17
	Central	49.24	21.21	17
	Eastern	67.20	64.71	5
	Total	51.49	32.85	81

Southwestern (*M* = 46.21, *SD* = 21.53) and Central (*M* = 49.24, *SD* = 21.21) regions. Analyses for age at diagnosis were conducted with outliers deleted and the model remained non significant, *F* (3, 68) = 1.42, $p > .05$. Age at diagnosis was more similar between groups, with children in the Central region diagnosed earliest (*M* = 42.07, *SD* = 14.79), followed by children in the Southwestern (*M* = 42.22, *SD* = 16.68), Northern (*M* = 45.71, *SD* = 33.16) and Eastern (*M* = 67.20, *SD* = 64.71) regions of the province.

Data Screening

Data screening was conducted on dependent variables (i.e., age at initial concern, help-seeking delay and age at diagnosis) prior to statistical analyses. Children with Asperger's Disorder tended to have extreme values on many variables and were typically outliers in the data, so they were excluded from subsequent analyses. The remaining data set consisted of participants with Autistic Disorder and PDD-NOS. Data were re-screened and several variables were not normally distributed, including age at diagnosis, age at which parents became concerned about social development, age at which parents became concerned about medical problems or delays in milestones, age at the second appointment and age at the third appointment. Furthermore, age at which parents became concerned about social development, age at which parents became concerned about medical problems or delays in milestones were skewed in the positive direction. Three outliers were identified within the dataset. After investigating the outliers, it was decided to delete these participants from subsequent analyses because they more closely resembled children with Asperger's disorder. Analyses were conducted with outliers included, and with outliers deleted, and this did not change the significance of the findings. The resulting dataset consisted of 72 participants (51 children with Autistic

Disorder and 21 children with PDD-NOS). Participants were excluded from analyses in cases for which data were missing. Descriptive statistics for children excluded from analyses are provided in Table 12.

Correlational Analyses

Pearson correlations were conducted between all continuous variables, including date of birth, age at initial concern, the help-seeking delay, age at first appointment, age at second appointment, age at third appointment, age at diagnosis and SES. An intercorrelation matrix is provided in Table 13. Pearson correlations revealed significant correlations between date of birth and age at diagnosis, $r = -.39, p < .01$ and year of diagnosis, $r = .87, p < .01$. These results indicate that children with autism were diagnosed at younger ages over time. In addition, significant correlations were found between age at initial concern and age at the first, $r = .84, p < .01$, second, $r = .81, p < .01$ and third appointment, $r = .81, p < .01$, after parents' became concerned about their development. Thus, when parents became concerned about their children's development at later ages, their children were seen by professionals to address those concerns at later ages as well. Significant correlations were also found between the help-seeking delay and age at the first, $r = .61, p < .01$, second, $r = .62, p < .01$ and third appointment, $r = .60, p < .01$, after parents' became concerned about their development. This finding suggests that the longer parents waited before seeking help from professionals, the older their children were at subsequent appointments with professionals to address those concerns. Finally, age at diagnosis was significantly correlated with the help-seeking delay, $r = .44, p < .01$, and age at the first, $r = .67, p < .01$, second, $r = .73, p < .01$ and third appointment, $r = .77, p < .01$, after parents' became concerned about their development.

Table 12

Descriptive Statistics for Children Excluded from Analyses

Diagnosis	Birth Year	Gender	Birth Order	Region[a]	Age at initial concern	Help-seeking delay	Age at diagnosis
Asperger's	1985	Female	Middle	SW	1	41	78
Asperger's	1987	Male	Youngest	SW	36	12	108
Asperger's	1990	Male	Youngest	N	6	127	140
Asperger's	1994	Male	Oldest	C	36	12	79
Asperger's	1995	Male	Oldest	C	48	12	96
Asperger's	1996	Male	Oldest	C	18	18	73
PDD-NOS	1991	Male	Oldest	N	19	22	151
PDD-NOS	1993	Male	Middle	SW	18	6	96
Autistic Disorder	1991	Male	Youngest	N	1	17	147

Note. Values represent ages in months.

[a] Region: SW = Southwestern Ontario, N = Northern Ontario, C = Central Ontario

Table 13

Intercorrelations Between Continuous Variables.

	1	2	3	4	5	6	7	8	9
1. D.O.B	-	-	-	-	-	-	-	-	-
2. Age at initial concern	.01	-	-	-	-	-	-	-	-
3. Help-seeking delay	-.06	.11	-	-	-	-	-	-	-
4. Age 1st appointment	.01	.84**	.61**	-	-	-	-	-	-
5. Age 2nd appointment	-.03	.81**	.62**	.96**	-	-	-	-	-
6. Age 3rd appointment	-.002	.81**	.60**	.90**	.94**	-	-	-	-
7. Age at diagnosis	-.39**	.41	.44**	.67**	.73**	.77**	-	-	-
8. Year of diagnosis	.87**	.23	.12	.27	.24	.30*	.10	-	-
9. SES	-.10	-.004	.10	.03	.06	-.09	-.16	-.19	-

Note. Missing values are represented by the – symbol.
* Correlation is significant at the .05 level (2-tailed).
** Correlation is significant at the .01 level (2-tailed).

Results such as these indicate that the longer parents waited before seeking professional help, the older their children were at the time of diagnosis and similarly, the older children are the first, second and third appointment after parents became concerned about their development, the older children were at the time of diagnosis.

Main Hypotheses

A power analysis was conducted and the upper limit of power was found to be .70 to .80 for a medium effect size (Pilot & Beck, 2004). However, for the majority of analyses, power was compromised due to uneven cell sizes (i.e., 10 females versus 70 males), increasing the possibility of Type I error.

In order to examine the influence of gender, ethnicity, birth order and SES, *t*-tests for independent samples were conducted for the dependent variables (i.e., age at initial concern, the help-seeking delay and age at diagnosis). *T*-tests were conducted instead of ANOVAs because such analyses would be compromised due to uneven cell sizes and because there were significant correlations between dependent variables. For birth order, "only" children ($N = 5$) were excluded from analyses to increase power. For the independent variable SES, the sample was divided into a low SES group for those who obtained a raw SES score below the median (i.e., 42.03) and a high SES group for those who obtained a raw score above the median. Dividing the sample was preferred over using the Hollingshead categories to increase power (i.e., increase the number of participants in each group).

Hypothesis I. Demographic variables and age at initial concern.

1a: Gender. It was predicted that parents of female children would be concerned earlier than would parents of male children (e.g., Short & Schopler, 1988; De Giacomo &

Fombonne, 1998). Although the average age at initial concern was earlier for females (*M* = 17.22, *SD* = 7.21), compared to males (*M* = 20.00, *SD* = 13.91), there were no significant differences between groups $t(64) = .58, p > .05$. Means and standard deviations are provided in Table 14.

1b: Birth order. It was anticipated that parents of youngest children would be concerned about their children's development earlier than would parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1988). The average age at initial concern was 18.97 (*SD* = 11.72) months for youngest children, 17.62 (*SD* = 6.53) months for middle children and 24.38 (*SD* = 19.61) months for oldest children. There were no significant differences in age at initial concern between youngest and middle children, $t(43) = .39, p > .05$, youngest and oldest children, $t(46) = -1.20, p > .05$, or between middle and oldest children $t(27) = -1.19, p > .05$.

Exploratory Concerns. Ethnicity and socioeconomic status and their impact on age at initial concern were explored. Due to the lack of previous research in these areas, no explicit hypotheses were formulated. There were no significant differences in age at initial concern between Caucasian (*M* = 19.47, *SD* = 13.93), and non-Caucasian children (*M* = 20.75, *SD* = 5.75), $t(64) = -.26, p > .05$. The average age at initial concern was earlier for children in the high SES group (*M* = 17.54, *SD* = 11.50) compared to children in the low SES group (*M* = 19.38, *SD* = 9.77), but the difference was not significant, $t(55) = .65, p > .05$.

Table 14

Descriptive Statistics for Demographic Variables and Age in Months at Initial Concern

Variable	*M*	*SD*	*N*
Gender n.s.			
Male	20.00	13.91	57
Female	17.22	7.21	9
Ethnicity n.s.			
Caucasian	19.47	13.93	58
Non-Caucasian	20.75	5.75	8
Birth Order n.s.			
Only	13.80	6.57	5
Youngest	18.97	11.72	32
Middle	17.62	6.53	13
Oldest	24.38	19.61	16
SES n.s.			
Low	19.38	9.77	29
High	17.54	11.50	28

Hypothesis II. Initial help-seeking efforts by parents

It was predicted that the majority of parents would first seek help through informal sources, such as friends and family, before seeking help from formal sources, such as physicians or psychologists (e.g., Pavuluri, Luk & McGee, 1996; McMiller & Weisz, 1996). Parents were asked to indicate what they did in the time period immediately after they became concerned about their children's development (See Table 15). There were 123 responses offered by 69 parents in total. After becoming concerned about their children's development, 43.9% of parents indicated that they made an appointment with a doctor, or another health care practitioner, 19.5% of parents asked friends, family or co-workers for advice and 16.3% of parents looked for information in books, magazines, or the Internet. Parents also reported that they waited for improvement (10.6%), waited until the next appointment with a doctor or other health care practitioner (7.3%), consulted with a professional about their children's development (1.8%) or began working individually with their child (0.8%). Results do not support the hypothesis that parents first sought help through informal resources, as most parents reported that they immediately sought help from professionals.

Hypothesis III. Demographic variables and the help-seeking delay.

3a: Gender. It was predicted that parents of female children would seek help earlier than would parents of male children, as females with autism typically have more severe cognitive and adaptive deficits (e.g., Volkmar, Szatmari & Sparrow, 1993). Instead, the average help-seeking delay was longer for females ($M = 9.00$, $SD = 9.44$) compared to males ($M = 7.20$, $SD = 8.11$), although this difference was not significant, $t(57) = -.57$, $p > .05$. See Table 16 for means and standard deviations.

Table 15

Parents' First Steps After Becoming Concerned About Their Children's Development

Action	*N*	%
Made an appointment with a doctor	54	43.9
Asked friends, family for advice	24	19.5
Looked for information in books, magazines, or Internet	20	16.3
Waited for improvement	13	10.6
Waited until next appointment with doctor	9	7.3
Consulted with a professional	2	1.6
Worked individually with child	1	0.8
Total	123	100.0

Table 16

Descriptive Statistics for Demographic Variables and the Help-seeking Delay

Variable	*M*	*SD*	*N*
Gender n.s.			
Male	7.20	8.11	51
Female	9.00	9.44	8
Ethnicity n.s.			
Caucasian	7.34	8.17	53
Non-Caucasian	8.33	9.56	6
Birth Order n.s.			
Only	9.80	9.99	5
Youngest	7.96	8.53	26
Middle	4.92	3.23	12
Oldest	7.75	9.96	16
SES n.s.			
Low	7.70	8.95	27
High	6.58	7.28	24

Note. Values represent ages in months.

3b: Ethnicity. It was expected that non-Caucasian children would experience longer delays than would Caucasian children before receiving professional help (e.g., Flisher et al., 1997; Bussing, Zima, Gary & Garvan, 2003). The average help-seeking delay was slightly longer for non-Caucasian children ($M = 8.33$, $SD = 9.56$) compared to Caucasian children ($M = 7.34$, $SD = 8.17$); however, this difference was not significant, $t(57) = -.28, p > .05$.

3c: Birth order. It was anticipated that parents of youngest children would seek help earlier than would parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1998). The help-seeking delay was 7.96 ($SD = 8.53$) months for youngest children and 7.75 ($SD = 9.96$) months for older children and *t*-test revealed no significant difference between groups, $t(40) = .07, p > .05$. The assumption of homogeneity of variance was not met for *t*-tests between youngest children and middle children, and between middle children and oldest children (SPSS Inc., 2001). Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. There were no significant differences in the help-seeking delay between youngest children ($M = 7.96$, $SD = 8.53$) and middle children ($M = 4.92$, $SD = 3.23$), $t(35.23) = 1.59, p > .05$. Similarly, there were also no significant differences in the help-seeking delay between middle children ($M = 4.92$, $SD = 3.23$) and oldest children ($M = 7.75$, $SD = 9.96$), $t(19) = -1.07, p > .05$.

3d: Socioeconomic status. To the extent that health care resources are more accessible to individuals of high SES, it was predicted that the help-seeking delay would be shorter for children in the high SES group compared to children in the low SES group (e.g., De Giacomo & Fombonne, 1998). Although the help-seeking delay was slightly shorter for children in the high SES group ($M = 6.58$, $SD = 7.28$) compared to children in the low SES group ($M = 7.70$, $SD = 8.95$), this difference was not significant, $t(49) = .49$, $p > .05$.

Hypothesis IV. Barriers to professional help-seeking

Parents were asked to report what factors made it hard for them to take their children to a doctor. It was predicted that parents will believe that doctors will not take their concerns seriously, or practicality issues, such as transportation or lack of available child care, would be identified by parents as barriers to seeking help. There were 48 responses were provided by 35 parents (See Table 17). The majority of parents indicated that long waiting lists (39.6%), the belief that the doctor would not take their concerns about their child's development seriously (33.3%) and a lack of social support (10.4%) made it hard for them to take their child to a doctor. Parents also reported that difficulty finding a babysitter (4.2%) and the distance of the doctor's office from their home (4.2%) made it difficult to seek professional help, along with not having enough time (2.1%), transportation (2.1%), or available services in their region (2.1%). Results partially support the hypothesis that self-doubt in the form of believing doctors will not take their concerns seriously interferes with the help-seeking process. However, results also suggest that parents are encountering systematic barriers in the form of long waiting lists that are interfering with the help-seeking process.

In addition to examining barriers to professional help-seeking, an item on the research questionnaire also asked parents to indicate what factors made it "easy" to seek professional help. In total, there were 133 responses provided by 63 parents. Support

Table 17

Frequency of Factors that Influenced Help-seeking as Reported by Parents

Factor	*N*	%
Barrier		
Long waiting lists	19	39.6
Did not think doctor would take concern seriously	16	33.3
No social support	5	10.4
Could not find a babysitter	2	4.2
Distance, doctor's office was too far away	2	4.2
No transportation	1	2.1
Lack of available services	1	2.1
Not enough time	1	2.1
Other (unspecified)	1	2.1
Facilitator		
Support from spouse, family or friends	39	29.3
Flexible work schedule	34	25.6
Good relationship with child's doctor	31	23.3
Organizations or agencies	17	12.8
Short waiting lists	12	9.0

from family, friends and co-workers was reported to be the most common facilitator to seeking help (29.3%), followed by a flexible work schedule (25.6%), a good relationship with the child's doctor (23.3%), organizations or agencies (12.8%) and short waiting lists (9.0%).

Hypothesis V. Demographic variables and age at diagnosis

5a: Gender. As previous research has found that females with autism typically experience greater cognitive and adaptive deficits (e.g., Volkmar, Szatmari & Sparrow, 1993), it was hypothesized that females would be diagnosed with an autism spectrum disorder earlier than males. Although the average age at diagnosis was earlier for females ($M = 39.60$, $SD = 18.23$), compared to males ($M = 45.27$, $SD = 26.73$), this difference was not significant, $t(70) = .65, p > .05$. Table 18 provides means and standard deviations for hypothesis V.

5b: Ethnicity. It was predicted that non-Caucasian children would be diagnosed later than would Caucasian children, as the former group are thought to be underserviced with respect to health care services (Mandell, Listerud, Levy & Pinto-Martin, 2002). In contrast to this prediction, non-Caucasian children were diagnosed on average at 35.22 ($SD = 9.68$) months of age compared to 45.81 ($SD = 27.01$) months of age for Caucasian children; however, this difference was not significant, $t(70) = 1.16, p > .05$.

5c: Birth Order. As parents of youngest children were expected to seek help sooner than parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1998), it was similarly expected that youngest children would be diagnosed earlier than middle and oldest children. On average, youngest children were diagnosed at 38.79 ($SD = 12.54$) months of age, middle children were diagnosed at 47.73 ($SD = 39.94$) months of age and

Table 18

Descriptive Statistics for Demographic Variables and Age in Months at Diagnosis

Variable	*M*	*SD*	*N*
Gender n.s.			
Male	45.27	26.73	62
Female	39.60	18.23	10
Ethnicity n.s.			
Caucasian	45.81	27.01	63
Non-Caucasian	35.22	9.68	9
Birth Order n.s.			
Only	42.80	12.56	5
Youngest	38.79	12.54	33
Middle	47.73	39.94	15
Oldest	52.26	30.24	19
SES n.s.			
Low	47.61	28.87	31
High	39.35	17.68	31

oldest children were diagnosed at 52.26 (*SD* = 30.24) months of age. There were no significant differences in age at diagnosis between middle (*M* = 47.73, *SD* = 39.94) and oldest children (*M* = 52.26, *SD* = 30.24), *t*(32) = -.38, *p* > .05. The assumption of homogeneity of variance was not met for *t*-test between youngest children and middle children, and between youngest children and oldest children. Thus, a t-static was computed based on separate variance estimates and the degrees of freedom were adjusted downward to provide for a more conservative test, ensuring control of type 1 error. There were no significant differences in age at diagnosis between youngest children (*M* = 38.79, *SD* = 12.54) and middle children (*M* = 47.73, *SD* = 39.94), *t*(15.27) = -.85, *p* > .05. Similarly, there were also no significant differences in age at diagnosis between and youngest children (*M* = 38.79, *SD* = 12.54) and oldest children (*M* = 52.26, *SD* = 30.24), *t*(21.62) = -1.85, *p* > .05.

5d: Socioeconomic status. It was expected that children in low SES families would be diagnosed later than would children in high SES families, as the former group are thought to be under-serviced with respect to health care services (e.g., Flisher et al., 1997). On average, children in the high SES group (*M* = 39.35, *SD* = 17.68), were diagnosed earlier than children in the low SES group (*M* = 47.61, *SD* = 28.87); however, this difference was not significant, *t*(60) = 1.36, *p* > .05.

Exploratory Findings

The confirmation of an autism diagnosis is the first step that is needed before children are eligible to receive services. Since researchers continue to demonstrate the intensive behavioural intervention (IBI) treatment is most effective when implemented early (e.g., Harris & Handleman, 2000), it is important to understand variables that influence age at diagnosis. Results of the correlational analyses described previously revealed significant positive relationships between age at diagnosis and the help-seeking delay and age at first, second and third appointments, and a significant negative correlation between age at diagnosis and date of birth. Due to significant findings, it was thought to be worthwhile to conduct a multiple regression to further investigate the relationship between these variables and age at diagnosis. Data from children with Asperger's Disorder and three other children who were outliers within the data set were excluded. Variables entered in the model included children's date of birth, age at initial concern, and age at first appointment. Excluded variables included the help-seeking delay and age at second and third appointments. The help-seeking delay was excluded because it was calculated by subtracting children's age at the first appointment from children's age at which parents initially became concerned about their development. Because age at initial concern and age at first appointment were entered in the model, the help-seeking delay variable would be redundant. Age at second and third appointment was excluded because they were highly intercorrelated and approximately 48% of the sample was diagnosed with an autism spectrum disorder at the third appointment.

A standard multiple regression was conducted and the model was significant, ($F(3, 58) = 19.50, p < .01$). Date of birth ($\underline{sr}_i^2 = .05$) and age at first appointment ($\underline{sr}_i^2 = .02$) contributed significantly to the model. Age at initial concern was not significant, and the addition of this variable did not contribute any variability to the model ($\underline{sr}_i^2 = .00$). Altogether, 25% of the variance in age at diagnosis was predicted by date of birth, age at initial concern and age at first appointment. The result of the regression are displayed in Table 19.

Table 19

Summary of Standard Multiple Regression for Variables Predicting Age at Diagnosis

Variables	*B*	*SE B*	ß
Date of birth	-3.30	0.00	-0.21*
Age at initial concern	-1.80	0.25	-0.12
Age at first appointment	0.95	0.21	-0.78**

Note. $N = 61$

* $p < .05$, ** $p < .01$

Parents' Opinions About How to Improve the Autism Diagnostic System

Parents were asked to explain what they think should be done to improve the autism diagnostic system in Ontario and responses were provided by 44 parents. Following procedure recommended by Neuendorf (2002) for distillation of qualitative themes, categories for classification of parents' responses were developed after all responses had been viewed. Parents provided a total of 96 suggestions, 79 of which were classifiable according to seven derived themes (See Figure 2). For each parent who provided suggestions about how to improve the autism diagnostic system, one response per category was coded (i.e., multiple responses by one parent in the same category were treated as a single response). There were 17 responses provided by parents that were unclassifiable, generally because parents were describing their experiences. Table 20 provides examples of responses that were coded in each category that was developed. Parents believed that the autism diagnostic system would be improved by increasing education to medical doctors about autism spectrum disorders (30.4%), decreasing the amount of time on waiting lists (22.8%), having more professionals available to assess and diagnose autism (13.9%), providing information to parents about red-flags for autism (10.1%), implementing a "team approach" to assessment and diagnosis (7.6%), improving the co-ordination of assessment and diagnostic services (7.6%) and implementing systematic early screening for autism spectrum disorders (7.6%).

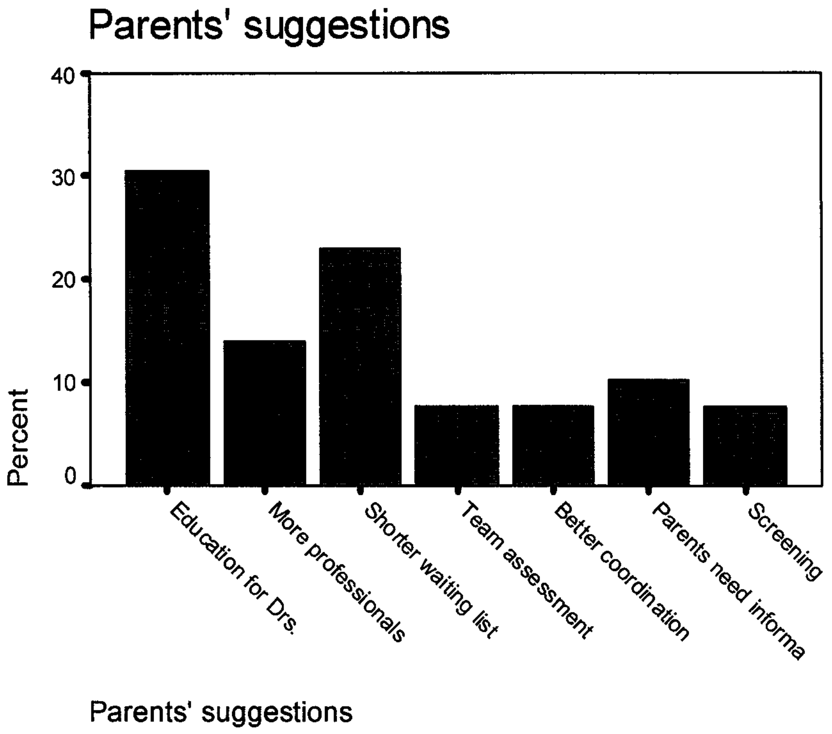

Figure 2. Percentage of parents' suggestions to improve the autism diagnostic system.

Table 20.

Examples of Parents' Responses about How to Improve the Autism Diagnostic System

Category
1. More education to medical doctors
"All graduates of medical school should be very well versed on ASD so that they can recognize the signs and thereby be willing to make a diagnosis."
"Pediatricians need to have more information on early signs of autism and Pervasive Developmental Disorders."
2. More professionals available
"Windsor/Essex county is in dire need of more qualified persons to give assessments at any age."
"Sault St. Marie needs more qualified people in almost all departments."
3. Shorten waiting lists
"The autism diagnostic system can be improved by short waiting lists to see specialist practitioners."
"Less waitlists would be key to receiving proper treatment."
4. Team assessment and diagnosis
"Team assessment absolutely necessary."
"Referral to developmental team where speech, assessment, etc. occur."

Table 20. (continued)

Category
5. Providing information to parents about autism
"Information sent in mail to all homes explaining red flags for autism."
"Mechanism to increase parental awareness about early red flags for developmental delays."
6. Improving the co-ordination services
"Streamline and coordinate access to professional services."
"Services need to be coordinated."
7. Early screening
"Primary care providers should administer developmental screeners."
"All family practice offices/public health units should have a questionnaire for moms and parents of toddlers with 3-4 basic questions regarding joint attention, shared response, and any loss of speech."
8. Unclassifiable
"We learned that professionals could be wrong that the we needed to trust our own instincts and sometimes say no."
"We were all over our city but never in the place where the people who diagnosis autism for a living were."

Chapter IV.

DISCUSSION

The present study investigated parents' experiences during the course of obtaining an autism diagnosis for their children. The present study utilized a Canadian sample and results are similar to that of other studies conducted in other areas of the world (e.g., Short & Schopler, 1988; Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997; De Giacomo & Fombonne, 1998; Baghdadi, Picot, Pascal, Pry, Aussilloux, 2003). Specifically, in the absence of routine screening procedures in Ontario, early symptoms of autism (e.g., language delays, social skills deficits, abnormal behaviours, delays in milestones) tend to be identified by children's parents. Subsequently, parents seek professional help for their concerns about their children's development, and doctors commonly tell parents not to worry or take additional action, or children are referred to another professional. This sequence is often repeated several times, as children are shuffled about between professionals before an autism diagnosis is confirmed. One parent who participated in the research reported that "*We knew he had autism when we first went to our general practitioner. He said he did not know a lot about it and of course referred us on, on, on and on.*" Thus, the process of navigating the autism diagnostic system appears to be lengthy not only for parents in the U.K. (e.g., Howlin & Moore, 1997; Baghdadi, Picot, Pascal, Pry, Aussilloux, 2003) and U.S.A. (e.g., Mandell, Listerud, Levy, & Pinto-Martin, 2002), but also for parents in Ontario.

The present study was concerned with identifying demographic variables (i.e., gender, ethnicity, birth order and SES) that influenced the age at initial concern, help-seeking delay and age at diagnosis. Although hypotheses were not supported statistically, possibly due to the small sample and low power as a result of unequal cell sizes, there were compelling trends in the predicted directions for the majority of analyses. It is likely that significant results would have been found in a larger sample size. Thus, additional research is needed to investigate the influence of demographic variables on the diagnostic process in a larger, more diverse sample.

Parents' Initial Concerns

In 75% of cases, mothers were the first ones to be concerned about their children's development. Medical doctors or other health care practitioners were the first to be concerned for only 5% of the sample, indicating that early symptoms of autism were first identified within the home. As such, it is important for all parents to be aware of developmental delays and early symptoms that are characteristic of autism so professional help can be sought immediately after such behaviours are identified. Approximately 10% of parents reported that providing information to parents about "red flags" for autism would make the autism diagnostic system more accessible. For example, one parent explained that there should be *"brochures/information sheets sent to all moms when their child is born. We could have got our son help earlier had we known!"*

Age at Initial Concern

On average, parents initially became concerned about their children's development when they were 19.71 months of age; comparable to findings from past research in this area (e.g., Short & Schopler, 1988; Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997; De Giacomo & Fombonne, 1998; Baghdadi, Picot, Pascal, Pry, Aussilloux, 2003). Although the average age at initial concern was earliest for children with Autistic Disorder, followed by children with PDD-NOS and children with Asperger's Disorder, there were no significant between group differences. Significant between group differences in the age at initial concern would likely have been found in a larger sample. In the present sample, the most common initial concerns were for abnormal behaviours, followed by language development, social skills and medical problems or delays in milestones, whereas in previous research (e.g., Smith, Chung & Vostanis, 1994; Howlin & Moore, 1997; De Giacomo & Fombonne, 1998), the most common initial concerns were for language development followed by social skills. Approximately 36% of the sample was diagnosed with Asperger's disorder or PDD-NOS according to parent-report and as such, delayed language development may not be as prevalent for these children (APA, 2000). Parents of children with Autistic Disorder were concerned about their social skills significantly sooner than parents of children with PDD-NOS. This finding is not surprising, given that the diagnostic criteria for PDD-NOS include symptom onset after age three, symptom severity at a sub-threshold level or atypical symptom presentation (APA, 2000).

Demographic variables and age at initial concern. It was predicted that parents of female children would be concerned earlier than would parents of male children (e.g., Short & Schopler, 1988; De Giacomo & Fombonne, 1998). Although the average age at initial concern was found to be earlier for females compared to males, this relationship was not significant. In addition, it was anticipated that parents of youngest children would be concerned about their children's development earlier than would parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1988). Consistent with this hypothesis, the average age at initial concern was earlier for middle and youngest children compared to parents of older children; however, this relationship was not significant. Ethnicity and socioeconomic status and their impact on age at initial concern were also explored, but due to the lack of previous research in these areas, no explicit hypotheses were formulated. The average age at initial concern was approximately one month earlier for Caucasian children compared to non-Caucasian children and this difference was not significant. Also, the average age at initial concern was earlier for children in the high SES group compared to children in the low SES group, and this relationship was not significant as well.

Help-seeking from Professionals

Before seeking professional help, most parents made an appointment with their children's doctor to address their concerns, asked friends or family for advice or looked for information in books or magazines before seeking help. In contrast to previous researchers who found that most parents initially sought help through informal resources before seeking professional help for their children's behaviour problems (e.g., Pavuluri, Luk & McGee, 1996), approximately 44% of parents in the current sample indicated that they sought professional help first. Parents indicated that social support, a flexible work schedule and having a good relationship with their child's doctor made it easy for them to seek professional help. When asked to indicate factors that made it hard for them to seek professional help, most parents listed long waiting lists and the belief that doctors would not take their concerns seriously. Such results suggest that parents encountered systematic barriers, such as wait lists, that resulted in increasing the amount of time to obtain an autism diagnosis. As reported by one parent who participated in the research, *"there is no point in diagnosing children early if they are just put on another waiting list* *for treatment, that they are told IBI ends at age 6 when they are on top of the list. It leaves parents in a most devastating situation."* Parents believed that decreasing the amount of time on wait lists and having more professionals available in their communities to assess and diagnose autism would make the autism diagnostic system more efficient (e.g., *"Shorten waiting lists by having more professionals to diagnose"*).

In the current sample, 19.5% of parents reported that they first went to their friends or family for advice immediately after they became concerned about their children's development and 29.3% of parents reported that social support made it easier for parents to seek professional help. These findings suggest that for parents of children with autism, social support is important and should be investigated through further research. In practice, it may be helpful to educate the general public about how to approach a friend or family member when they suspect their child has autism. For example, doctor's offices, or agencies that deal with families could provide such information in brochures or on websites. Additionally, it may be helpful for support groups to be available for families and friends of individuals with autism to allow them to learn more about the disorder through social relationships with others.

The Help-seeking Delay

The average amount of time that had passed between the age at which parents initially became concerned about their children's development and the age at the first appointment with a professional to address their concerns was 10.38 months. The help-seeking delay was approximately twice as long as in previous studies (e.g., Howlin & Moore, 1997; De Giacomo & Fombonne, 1998). The help-seeking delay was approximately 7 ½ months for children with Autistic Disorder, 8 ½ months for children with PDD-NOS and 37 months for children with Asperger's Disorder; however, significant between group differences were not found. It is likely that significant between group differences would have been found in a larger sample. Children with Asperger's Disorder theoretically have restricted, stereotyped behaviours and deficits in socialization that are present in the context of relatively intact cognitive and language skills. Although parents of children with Asperger's Disorder were concerned on average when their children were approximately 24 months of age, deficits in socialization may not have been perceived by parents to be severe enough to warrant professional intervention until deficits became more prominent, most likely when children had the opportunity to interact with same-age peers within the school setting.

Demographic variables and the help-seeking delay. It was predicted that parents of female children would seek help earlier than would parents of male children, as females with autism typically have more severe cognitive and adaptive deficits (e.g., Volkmar, Szatmari & Sparrow, 1993). Although parents of females were concerned about their development earlier than parents of males, the average help-seeking delay was approximately 1 ½ months longer for females compared to males. Although this finding was not statistically significant, it warrants further investigation. Early symptoms of autism in females may not have been perceived to be severe enough to warrant professional attention. Alternatively, males may have demonstrated more "acting out" behaviours such as tantrums, compared to females, who may have demonstrated more repetitive behaviours, for example. Thus, gender differences in the presentation of early symptoms of autism may have influenced parents' help-seeking behaviours.

In addition, it was expected that non-Caucasian children would experience longer delays than would Caucasian children before receiving professional help (e.g., Flisher et al., 1997; Bussing, Zima, Gary & Garvan, 2003). In the current sample, the average help-seeking delay was approximately one month longer for non-Caucasian children compared to Caucasian children; however, this difference was not significant. Parents of youngest children were expected to seek help earlier than parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1998). There were no significant between group differences in the help-seeking delay, although the help-seeking delay was shortest for middle children compared to youngest and oldest children. It was predicted that the help-seeking delay would be shorter for children in the high SES group compared to children in the low SES group (e.g., De Giacomo & Fombonne, 1998). Although the help-seeking delay was approximately one month shorter for children in the high SES group than children in the low SES group, this difference was not significant.

Professionals' Responses to Parents' Concerns

At the first appointment with professionals after parents became concerned about their children's development, most children were referred to another professional or parents were told to "wait and see" if their children's behaviour improved. At the second appointment, most children were referred to another professional or diagnosed with an autism spectrum disorder, while at the third appointment, most children were diagnosed with an autism spectrum disorder or referred to another professional. The diagnostic process was lengthy, as the time span between the average age at the first appointment and the average age at the third appointment was 11.55 months for children with Autistic Disorder, 25.03 months for children with Asperger's Disorder and 15.33 months for children with PDD-NOS. Also, the research questionnaire inquired only about the first three appointments after parents became concerned about their children's development. As such, the actual amount of time spent navigating the autism diagnostic system is likely quite longer before the confirmation of a diagnosis.

When children are referred, they are often placed on waiting lists for months before they can see a professional. Frequent referrals results in increasing age of diagnosis, and consequently, decreasing the amount of time that children are eligible for intensive behavioral intervention. One parent expressed that "*We were put on a waiting list way too long even though we as parents already knew. It took too long to get a piece of paper in order to get services for him. If a mother says her child is not developing normally she should be taken very seriously and not put on a 12-18 month waiting list. A mother knows!*"

Age at Diagnosis

The average age at diagnosis was was 51.49 months, or approximately 4.29 years of age. In the present study, children were diagnosed approximately 1 ¾ years earlier than children in Howlin and Moore's (1997) study. Although Howlin and Moore (1997)'s sample was demographically similar, it was much larger than that of the present study and this may account for the discrepancy. In addition, the health care system is different in Ontario compared to the U.K. and the sample utilized in the current research was a younger cohort than children in Howlin and Moore's (1997) study. Children with Autistic Disorder were diagnosed earliest, followed by children with PDD-NOS and children with Asperger's Disorder. Children with Asperger's Disorder were found to be significantly older than children with Autistic Disorder at the time of diagnosis. When looking at geographical differences in the age at diagnosis, children in the Eastern regions of Ontario were diagnosed later than children in other regions of the province. However, due to the small sample size of children who resided in the Eastern region ($N = 5$), additional research is needed to investigate whether autism services are more available and sophisticated in some regions of the province compared to other regions.

Demographic Variables and Age at Diagnosis

As previous research has found that females with autism typically experience greater cognitive and adaptive deficits (e.g., Volkmar, Szatmari & Sparrow, 1993), it was hypothesized that females would be diagnosed with an autism spectrum disorder earlier than males. Although the average age at diagnosis was earlier for females compared to males, this difference was not significant. Also, it was predicted that non-Caucasian children would be diagnosed later than would Caucasian children, as the former group are thought to be underserviced with respect to health care services (Mandell, Listerud, Levy & Pinto-Martin, 2002). In contrast to this prediction, the average age at diagnosis for non-Caucasian children was ten months earlier than for Caucasian children; however, this difference was not significant. Potential reasons for this difference should be investigated through further research. For example, doctors may have found early symptoms of autism to be more salient in Non-Caucasian children than in Caucasian children.

As parents of youngest children were expected to seek help sooner than parents of middle and oldest children (e.g., De Giacomo & Fombonne, 1998), it was similarly expected that youngest children would be diagnosed earlier than middle and oldest children. Although youngest children were diagnosed at 38.79 months of age on average, middle children were diagnosed at 47.73 months of age and oldest children were diagnosed at 52.26 months of age, there were no significant between group differences. Such between group differences would likely be significant in a larger sample.

It was expected that children in low SES families will be diagnosed later than would children in high SES families, as the former group are thought to be under-serviced with respect to health care services (e.g., Flisher et al., 1997). On average, children in the high SES group were diagnosed earlier than children in the low SES group; however, this difference was not significant. Parents who participated in the research were in a higher SES bracket than the majority of residents of Ontario. It is likely that such differences would be more pronounced in a sample that was more representative with respect to SES.

Parents' Experiences

Parents were asked on the research questionnaire to include any comments that were relevant to their experiences. It appears that the majority of parents were not satisfied with the autism diagnostic system and that parents encountered difficulties obtaining an autism diagnosis for their children (e.g., *"Developmental issues largely ignored despite our concerns"*). These experiences tend to be common for parents of children with autism (Howlin & Moore, 1997; Maurice, Mannion, Letso & Perry, 2001). As stated by one parent who participated in the present research, "*When you're a first time mom or if you don't have family support or language barriers or the lack of knowledge (on autism) you don't know there is a problem with your child. Add to that "wait and see" doctors and waiting lists for treatment – your child has slipped away and you've lost valuable time for treatment.*"

Several parents who participated in the research believed that professionals had difficulty mentioning autism. When providing feedback, it is important for professionals to talk about prognosis, options for intervention and local resources, while providing hope to families (Nissenbaum, Tollesfson & Reese, 2002). For example, one parent reported that "*the psychiatrist was most concerned about giving my child a label and whether the diagnosis was right or wrong. The psychiatrist couldn't seem to understand a diagnosis was required in order to be able to access many services and funding.*" In addition, one parent indicated that the confirmation of an autism diagnosis was an important step for their family: "*Looking back we both recall that the diagnosis and the introduction of the "a" word - autism - did not devastate us. It propelled us into curious and energetic action.*"

Children with Asperger's Disorder

Children with Asperger's Disorder warrant further discussion because they stood out dramatically from children with Autistic Disorder and PDD-NOS. Asperger's Disorder appears to be difficult to diagnose relative to Autistic Disorder and PDD-NOS. In general, parents of children with Asperger's Disorder were concerned about their development at later ages, the help-seeking delay was lengthy, and the age at diagnosis was too late for children to be eligible for intensive behavioural intervention. As a result, children with Asperger's Disorder will have missed out on opportunities to improve their developmental outcomes through behavioural intensive intervention. Thus, children with Asperger's Disorder are relatively underserviced within the autism spectrum, and this likely has a devastating impact on these children and their families. Improved methods of recognition and diagnosis are needed for children with Asperger's Disorder who are typically thought of as being "high-functioning" with respect to symptomatology, and additional research should be conducted to understand how to better serve children with Asperger's Disorder.

In summary, the research did not find a significant relationship between child demographic variables (i.e., gender, ethnicity, birth order and SES) and age at initial concern, the help-seeking delay and age at diagnosis. Other analyses revealed highly significant intercorrelations between variables, suggesting that system variables are superseding child variables. It appears that the autism diagnostic system is currently overloaded. Children spend months on waiting lists before seeing specialists and this results in increasing the age at which children are diagnosed with autism. However, the age at which parents become concerned about their children's development does have an impact on how soon their children will be diagnosed with an autism spectrum disorder. In addition, the delay in help-seeking also has an impact on age at diagnosis and based on the results of the current study, it is recommended that parents seek professional help immediately after becoming concerned about their children's development. Finally, there is evidence to suggest that the autism diagnostic system in Ontario has become more efficient over time, as there was a significant negative correlation between year of birth and age at diagnosis. Although this may imply that there have been improvements in professionals' ability to identify autism spectrum disorders, additional research indicates that early signs of autism continue to be overlooked by paediatricians (Kaplan, 2005).

Limitations of the Current Study

The current research was limited in several areas. First, as the sample consisted primarily of parent members of the Autism Society of Ontario, the sample may not have been representative of the wider population of parents of children with autism throughout the province. Second, statistical power was compromised as a result of the small sample size. Third, parents' recall of past events during their children's early years may have been distorted due to memory decay. In addition, recall of past events may have been influenced by current knowledge of their children's behaviours and about autism spectrum disorders in general. Yet, the majority of research in this area has been retrospective in nature and thus is vulnerable to these alternative interpretations (Short & Schopler, 1988). Finally, the lack of a control group precludes formation of sound conclusions about specific help-seeking behaviours of parents of children with autism. An appropriate control group could include parents of children with other disabilities, such as Attention Deficit Hyperactive Disorder (ADHD), for example. Future research utilizing a control group of parents of children with other disabilities would permit an examination of help-seeking behaviours that are unique to parents of children with autism.

Several recommendations are offered in order to increase sample size when conducting research utilizing a population of parents of children with autism. It is important for the researcher to build a relationship with the autism community through involvement in autism organizations, such as the Autism Society of Ontario, or by attending functions in which parents of children with autism will be present. Furthermore, it is important to raise awareness about the research within the community through word of mouth, or by posting flyers in locations that parents visit, such as doctor's offices or day care centres.

Implications

The current research suggests that navigating the autism diagnostic system is a lengthy process that involves frequent visits to health care professionals before the confirmation of an autism diagnosis. Furthermore, it seems as if parents are encountering systematic barriers in the form of long waiting lists and a lack of coordination of services between health care professionals. These barriers interfere with early diagnosis. Approximately 8% of parents believed that implementing a "team approach" to assessment and diagnosis would improve the autism diagnostic system. Currently in Ontario, Children's Mental Health Centres that are funded through the Ministry of Children and Youth Services are available to assess and diagnose children; however, increased funding is needed to better meet the needs of children with autism.

Systematic Infant Screening

The autism diagnostic process would be best improved by the implementation of systematic infant screening. Screening involves the administration of standardized screening instruments or the elicitation of parents' concerns about their child's development to identify children who are at risk for autism (Filipek et al., 1999). Autism-specific screening tools, such as the Checklist for Autism in Toddlers (CHAT; Baird et al., 2000), investigates deficits in infancy in areas of pretend play, proto-declarative pointing, and gaze for children who are 18 months old. Screening enables earlier diagnoses of autism, which allows children greater opportunities to benefit from intensive behavioural intervention. Effective screening is a two-level process (Filipek et al., 1999). Children should be evaluated for developmental disabilities at every well-child visit to a general practitioner, pediatrician or nurse practitioner (Filipek et al., 1999) and the

American Academy of Pediatrics (2000) recommends that by age 2, children should have 10 well-child visits. Second, children who were found to be at-risk for autism should be further evaluated by specialists to differentiate autism from other developmental disabilities (Filipek et al., 1999). In theory, this process provides ample opportunity to identify at-risk children, however in practice, less than 30 % of health care practitioners routinely administer screening tests to children (Filipek et al., 1999).

Additionally, it is important to investigate the role of other professionals in the screening process. Although the research questionnaire inquired about the number of times children were seen by nurse practitioners, no children were seen by nurse practitioners according to parent report. Nurse practitioners should be utilized more by the health care system in Ontario to screen children for autism. Essentially, all professionals and caregivers that have contact with young children, such as dentists, day care staff, and teachers, should be trained to screen for autism.

Future Directions

Future research should be directed towards improving methods of recognition of autism spectrum disorders in very young children. For example, researchers have demonstrated that infants who are later diagnosed with autism demonstrate symptoms in infancy, possibly as early as 6 months of age (Zwaigenbaum et al., 2005). The development of screening measures to identify these early symptoms would theoretically enable children to be diagnosed in infancy, provided that such screening measures are routinely utilized in practice. Future research should also be conducted in collaboration with medical schools to examine the quantity and quality of didactic instruction and practical experience with autism identification. In short, future research should be directed towards the development of efficient screening measures, combined with the systematic implementation of these measures by medical professionals.

In the near future, genetic screening for autism may be an option for children at birth (Cure Autism Now, 2005). As genetic screening would allow children at-risk for autism to be identified at birth, theoretically, some of the difficulties associated with autism identification would be eliminated. However, approximately 25% of children who currently have autism in Ontario are receiving intensive behavioural interventions because only the most severe children with autism younger than six years of age are eligible for intensive behavioural interventions (Autism Society of Ontario, 2005). Increasing the province's sophistication in autism identification would necessitate an increase in government funding devoted to intensive behavioural intervention for children with autism.

In summary, the present study investigated parents' experiences during the course of obtaining an autism diagnosis for their children. Although results of the research suggest that the autism diagnostic system is becoming more efficient over time, improvements are needed in several areas, as children are currently being diagnosed too late to benefit from, or be eligible for intensive behavioural interventions. Specifically, future research should be directed towards the development of screening measures and towards the most effective means of systematically administering these measures to children.

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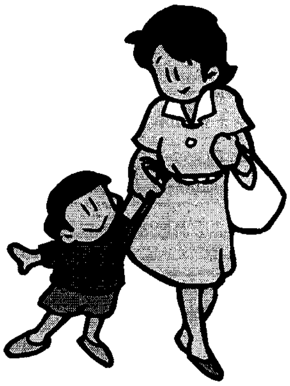
Appendix A: Recruitment Flyer

PARENTS: YOUR OPINION IS NEEDED!



I am a graduate student in Child Clinical Psychology at the University of Windsor and am conducting a study on parents' experiences getting an autism diagnosis for their children. If you are the parent of a child with an autism spectrum disorder, I would like to know about your first concerns about your child's development, your experiences getting professional help and your opinion about how the autism diagnostic system can be improved. Participating in the research is anonymous; you do not have to give your name. You have the choice of receiving a questionnaire in the mail or completing a telephone interview at your convenience. This research is being supervised by Dr. Marcia Gragg, Ph.D., C. Psych.

Appendix B: Diagnostic Experiences Questionnaire

Navigating the Autism Diagnostic System: Implications for Earlier Identification

This study is on you and your child's experiences in the autism diagnostic system. We would like to know how **you think** the autism diagnostic system could be improved.

<u>Please complete the following information about **your child.**</u>

1. What is your child's diagnosis in the autism spectrum?

   ☐ Autism ☐ Childhood Disintegrative Disorder
   ☐ Asperger's Disorder ☐ Rett's Disorder
   ☐ Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
   ☐ Other (Please specify):

2. In what year was your child diagnosed? (e.g., 1999)

3. How old was your child when given this diagnosis? Years: Months:

4. Are your child's language abilities equal to his/her same-age peers?

   ☐ Yes ☐ No

5. Are your child's intellectual abilities equal to his/her same-age peers?

   ☐ Yes ☐ No

6. Child's gender:

   ☐ Male ☐ Female

7. Your child's date of birth: Year: Month: Day:

8. Your child's first language:

   ☐ English ☐ French
   ☐ Other (Please Specify):

9. Was your child born in Canada?

☐ Yes ☐ No, my child was born in

10. What is your child's ethnicity?

☐ White/Caucasian	☐ Black/Caribbean/African Canadian
☐ Hispanic/Latino	☐ Arabic/Middle Eastern
☐ Native Canadian	☐ Asian/Pacific Islander
☐ Other (Please Specify)	

11. Your child has:

☐ No other siblings		
☐ Younger sibling(s)	Ages:	Gender:
☐ Older siblings(s)	Ages:	Gender:

12. Who was the first person to become concerned about your child's development?

☐ Myself
☐ Day care staff or teacher
☐ My spouse
☐ My child's doctor
☐ Family member (grandparent, aunt, cousin)
☐ Another health care practitioner (e.g. nurse, dentist)
☐ Other (please specify):

13. What were your first concerns? (Check all that apply) How old was your child when you first became concerned? Please number the boxes in order of your concern (1=first, 2=second, 3=third, 4=fourth)

☐ **Language Ability** **Years:** _______ **Months:** _______

Some examples of concerns about language ability may include: no speaking, late talking, not responding to name or gestures

☐ **Social Skills** **Years:** _______ **Months:** _______

Some examples of concerns about social skills may include: no smiling, no facial expression, no eye-contact

☐ **Abnormal Behaviours Years: ________ Months: ________**

Some examples of concerns about abnormal behaviours may include: odd attachment to objects, repetitive behaviours, tantrums, abnormal play

☐ **Medical Concerns/Delays Years: ________ Months: ________**

Some examples of concerns about medical concerns or delays may include: seizures, concerns about hearing, clumsiness, late walking

☐ **I was not worried until ______________ expressed a concern about my child's development**

14. What did you do when you **first** became concerned? (Check all that apply)

☐ Waited until next appointment with doctor or other health care practitioner
☐ Looked for information in books, magazines, or Internet
☐ Waited for improvement
☐ Asked friends, family or coworkers for advice
☐ Made an appointment with a doctor or other health care practitioner
☐ Other (Please specify)

15. Please check any problems that made it **hard for you** to take your child to a doctor (Check all that apply)

☐ Not enough time
☐ No transportation
☐ Distance, doctor's office was too far away
☐ Could not find a babysitter
☐ Did not think doctor would take concern seriously
☐ Other (Please Specify)
☐ Could not get time off work
☐ Long waiting lists

16. Please check any thing that made it **easy for you** to take your child to a doctor (Check all that apply)

☐ Short waiting lists
☐ Flexible work schedule
☐ Good relationship with your child's doctor
☐ Organizations or Agencies (Please Specify)
☐ Other (Please Specify)
☐ Support from spouse, family or friends

Please complete the following questions about appointments (with doctors, or other professionals) **after** you or someone else became concerned about your child's development. (Please indicate if this does not apply to you)

First Appointment

A. Your Child's Age:

Years: Months:

B. Professional:

☐ Medical doctor or general practitioner
☐ Pediatrician
☐ Nurse practitioner
☐ Child Psychologist
☐ Psychiatrist
☐ Other (Please Specify)

C. Outcome:

☐ Professional said to "wait and see" if behaviour/development improves
☐ My child was referred to another professional
☐ Professional said child was developing normally
☐ My child was diagnosed with
☐ Other (Please Specify)

Please use the space provided (and the other side of the paper if necessary) to let us know how you think the autism diagnostic system can be improved.

Second Appointment

Please indicate if this does not apply to you ☐

A. Your Child's Age:

Years: Months:

B. Professional:

☐ Medical doctor or general practitioner
☐ Pediatrician
☐ Nurse practitioner
☐ Child Psychologist
☐ Psychiatrist
☐ Other (Please Specify)

C. Outcome:

☐ Professional said to "wait and see" if behaviour/development improves
☐ My child was referred to another professional
☐ Professional said child was developing normally
☐ My child was diagnosed with
☐ Other (Please Specify)

Please use the space provided (and the other side of the paper if necessary) to let us know how you think the autism diagnostic system can be improved.

__Third Appointment__

(Please indicate if this does not apply to you) ☐

A. Your Child's Age:

Years: Months:

B. Professional:

☐ Medical doctor or general practitioner
☐ Pediatrician
☐ Nurse practitioner
☐ Child Psychologist
☐ Psychiatrist
☐ Other (Please Specify)

C. Outcome:

☐ Professional said to "wait and see" if behaviour/development improves
☐ My child was referred to another professional
☐ Professional said child was developing normally
☐ My child was diagnosed with
☐ Other (Please Specify)

Please use the space provided (and the other side of the paper if necessary) to let us know how you think the autism diagnostic system can be improved.

Now we would like to know a little bit about you. This helps us describe parents who agreed to take part in the study. The information that you provide is confidential. Please do not include your or your child's name on the questionnaire.

<u>Please complete the following information about **yourself.**</u>

1. Your Age in Years:

2. Your Relationship with the child:

☐ Mother, Biological	☐ Father, Biological
☐ Step-mother	☐ Step-father
☐ Adopted Mother	☐ Adopted Father
☐ Other (Please Specify)	

3. Your first language:

☐ English	☐ French
☐ Other (Please Specify)	

4. Were you born in Canada?

☐ Yes ☐ No, I was born in

5. Was your child's other parent born in Canada?

☐ Yes ☐ No, he/she was born in

6. What is your ethnicity?

☐ White/Caucasian	☐ Black/Caribbean/African Canadian
☐ Hispanic/Latino	☐ Arabic/Middle Eastern
☐ Native Canadian	☐ Asian/Pacific Islander
☐ Other (Please Specify)	

7. Your Marital Status:

☐ Single	☐ Separated
☐ Married	☐ Widowed
☐ Divorced	

8. Your Area of Residence:

☐ City of Windsor	☐ Peterborough
☐ Toronto	☐ Ottawa
☐ Sarnia	☐ Kingston
☐ Chatham	☐ Leamington
☐ Other (Please Specify)	

9. Are you employed?

☐ No ☐ Yes, working as

10. What is the highest level of education that you completed?

☐ Grade school	☐ Completed College/University
☐ High school	☐ Post-Graduate school
☐ Some College/University	

11. If you are married, is your spouse employed?

☐ No ☐ Yes, working as

12. If you are married, what is the highest level of education that your spouse completed?

☐ Grade school	☐ Completed College/University
☐ High school	☐ Post-Graduate school
☐ Some College/University	

13. Do you have a family doctor?

☐ Yes
☐ No

Appendix C: Letter of Information

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NAVIGATING THE AUTISM DIAGNOSTIC SYSTEM: IMPLICATION FOR EARLIER IDENTIFICATION

Letter of Information

PURPOSE OF THE STUDY

You are asked to participate in a study by Alison Spadafora, B.A., from the Psychology Department at the University of Windsor as part of the requirements for her Master's degree in Child Clinical Psychology. The study will look at parents' experiences in the autism diagnostic system. I would like to know about your first concerns about your child's development, experiences getting professional help and your opinion about how the autism diagnostic system can be improved. The study is being supervised by Dr. Marcia Gragg, Ph.D., C. Psych. If you have any questions or concerns, please feel free to contact her at 253-3000 ext. 2227.

PROCEDURES

If you volunteer to participate in the study, we will ask you to do the following things:

1) Complete a questionnaire. This will take approximately 20 minutes.
2) If you have filled out this questionnaire on a previous occasion, you do not have to fill it out again.
3) Return the questionnaire in the stamped, addressed envelope that is provided.

POTENTIAL RISKS

There are no risks or discomforts expected as a result of your participation.

POTENTIAL BENEFITS

You will not directly benefit from participating in the study. Your participation will provide valuable information about the autism diagnostic system in our community. We would like to know how you think the autism diagnostic system could be improved to make it more helpful and accessible to families. Results of the research will be posted on-line at http://cronus.uwindsor.ca/users/m/mgragg/main.nsf/ by September 31, 2004. It is our goal that this research will be published in a scientific journal.

PAYMENT FOR PARTICIPATION

You will not be paid for participating in the research. However, you have the option of being included in a **draw for 100$** that will take place on July 31, 2004. To be included in the draw, we ask that you fill out your name, phone number and e-mail address (if

Appendix D: Recruitment Letter

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I am a graduate student at the University of Windsor in Child Clinical Psychology and in the final stages of collecting data for my Master's thesis, entitled *"Navigating the Autism Diagnostic System: Implications for Earlier Identification."* The study deals with parents' experiences during the course of obtaining an autism diagnosis for their children, their experiences getting professional help, and their opinions about how the autism diagnostic system can be improved.

To date, the majority of parents who have participated in my research were members of the Windsor Chapter of the Autism Society of Ontario, recruited at the Annual General Meeting on March 29, 2004. In order to ensure that parents in other areas of Ontario are represented in the research, I have included 10 questionnaires that take approximately 15 minutes to complete. I would really appreciate if you could forward these packages to 10 families who reside in the Chatham-Kent area. Parents who participate are eligible to be included in a draw for $100 that will take place on July 31, 2004.

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

Sincerely,

Alison Spadafora
Department of Psychology

VITA AUCTORIS

NAME:	Alison Ann Spadafora
PLACE OF BIRTH:	Windsor, Ontario
YEAR OF BIRTH:	1979
EDUCATION:	Walkerville Collegiate Institute 1993-1997
	University of Windsor 1997-2001 (B.A. Honours)
	University of Windsor 2002-2005 M.A.