

**SOCIAL DETERMINANTS OF HEALTH AND AUTISM SPECTRUM  
DISORDER**

**SOCIAL DETERMINANTS OF HEALTH OF CHILDREN WITH AUTISM  
SPECTRUM DISORDER: A POPULATION LEVEL STUDY**

**By AYESHA SIDDIQUA, B.Sc., M.Sc.**

**A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the  
Requirements for the Degree of Doctor of Philosophy**

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## **LAY ABSTRACT**

There is limited information on health of children with Autism Spectrum Disorder (ASD) in relation to the neighbourhoods where they live. This study shows the number of children with ASD in a neighbourhood ranged from zero to as high as 21 across provinces and territories in Canada. Additionally, higher neighbourhood socioeconomic status was associated with better developmental health among children with ASD in Ontario, British Columbia, Manitoba, and Newfoundland and Labrador. In Ontario, having a primary care provider with domestic medical training was associated with an earlier age of ASD diagnosis compared to having a primary care provider with foreign medical training – although further exploration is required to examine whether other factors moderate this association. These findings can help guide the provision of early intervention services to children with ASD according to areas of need, as well as inform ASD related education training among primary care providers.

## ABSTRACT

Autism Spectrum Disorder (ASD) is one of the most commonly diagnosed neurodevelopmental disorders in Canada, with significant social and economic cost to society. The goal of this dissertation was to systematically examine the impact of social determinants on health of children with ASD. This was achieved through three studies, where the first two were pan-Canadian in scope and the third was a case study in Ontario. The first study examined the prevalence and developmental health of kindergarten children with ASD at the neighbourhood level. The second study examined the relationship between neighbourhood socioeconomic status (SES) and developmental health of children with ASD. Using Ontario as a case study province, the third study examined the relationship between characteristics of primary care providers and children with ASD with their age at diagnosis of this disorder. Each of these studies were conducted as population-based cohort studies where linked health, education, and administrative data were used. Following are the main findings from the three studies: (1) across provinces and territories, the number of children with ASD per neighbourhood ranged from zero to 21; (2) across provinces and territories, there was no consistent association between the size of spatial cluster of children with ASD in neighbourhoods, indicated by the number of children with ASD in a neighbourhood, and their developmental vulnerability; (3) in Ontario, British Columbia, Manitoba, and Newfoundland and Labrador, higher neighbourhood SES was associated with lower likelihood of developmental vulnerability; (4), in Ontario, children with primary care providers with foreign medical training had older age at ASD diagnosis than children with primary care providers with domestic medical training. Across Canada, these findings can help target areas of need and guide the delivery of early intervention services accordingly, whereas in Ontario, they can also help inform ASD related education training for primary care providers.

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## LIST OF ABBREVIATIONS

- ABA: Applied Behaviour Analysis
- ASD: Autism Spectrum Disorder
- CAPE: Client Agency Program Enrolment database
- CIHI: Canadian Institute of Health Information
- Cox PH: Cox proportional hazards
- CIHR: Canadian Institute of Health Research
- CPS: Canadian Paediatric Society
- DA: Dissemination area
- DAD: Canadian Institute for Health Information Discharge Abstract Database
- DB: Dissemination block
- DSM – 5: Diagnostic and Statistical Manual of Mental Disorders – 5th Edition
- EDI: Early Development Instrument
- E/FSL: English or French as a Second Language Status
- EIBI: Early Intensive Behavioural Intervention
- IPDB: ICES Physician Database
- IRCC: Immigrants, Refugees and Citizenship Canada’s Permanent Resident Database
- MDT: Multidisciplinary team
- MOHLTC: Ontario Ministry of Health and Long-Term Care
- NACRS: National Ambulatory Care Reporting System
- OHIP: Ontario Health Insurance Plan Claims database
- ONMARG: Ontario Marginalization Index database
- PALS: Participation and Activity Limitations Survey
- PCCF: Postal Code Conversion File
- RPDB: Registered Person’s Database
- SES: Socioeconomic status



## **DECLARATION OF ACADEMIC ACHIEVEMENT**

### Chapter One: Introduction

This chapter is unpublished. AS is the sole author.

### Chapter Two: Neighbourhood-level prevalence of teacher-reported Autism Spectrum Disorder among kindergarten children in Canada: A population level study

This chapter is published in the Social Science and Medicine – Population Health Journal. AS and MJ conceived the study idea. AS contributed substantially to study design, analysis and interpretation of data, as well as drafting the manuscript. All authors assisted in drafting the manuscript and revised it critically for important intellectual content.

### Chapter Three: Association between neighbourhood socioeconomic status and developmental vulnerability of kindergarten children with Autism Spectrum Disorder: A population level study

This chapter has been submitted to the Social Science and Medicine – Population Health Journal. AS and MJ conceived the study idea. AS contributed substantially to study design, analysis and interpretation of data, as well as drafting the manuscript. All authors assisted in drafting the manuscript and revised it critically for important intellectual content.

### Chapter Four: Primary care provider and child characteristics associated with age of diagnosis of Autism Spectrum Disorder: A population-based cohort study

This chapter is unpublished. AS, MJ, and NS conceived the study idea. AS contributed substantially to study design, analysis and interpretation of data, as well as drafting the chapter. All authors assisted in drafting the chapter and revised it critically for important intellectual content.

Chapter Five: Discussion

This chapter is unpublished. AS is the sole author.

## **Chapter One: Introduction**

### **1.1 Children with Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is a commonly diagnosed neurodevelopmental disorder in Canada, with a national prevalence estimate of 1 per 66 children diagnosed in 2015 (Public Health Agency of Canada, 2018). It is a heterogeneous, neurological disorder with no unifying pathological or neurobiological etiology (Geschwind & Levitt, 2007). Current evidence suggests that causes of ASD can be multifactorial, including genetic, epigenetic, as well as nongenetic factors which act in combination through diverse pathways (Anagnostou et al., 2014). While there is much evidence that ASD has a strong genetic component, there is yet no valid biological marker for this disorder (Lord, Cook, Leventhal, & Amaral, 2000). Being male has been identified as one of the greatest risk factors of ASD (Lord et al., 2000).

ASD is a complex lifelong condition with core dysfunctions occurring in two behavioural domains: difficulties in social communication and social interaction, as well as restricted, repetitive behaviours and interests (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). A review by Lord et al. (2000) shows communication disorders include failure to acquire speech, use of stereotyped speech, and difficulties in having conversations. This review also shows that socialization impairments include lack of social-emotional reciprocity, poor use of nonverbal communication, and difficulty in peer relations, whereas restricted interests and repetitive behaviours include unusual preoccupations, repetitive hand and finger movements, and compulsive behaviours and

rituals. Some children manifest the signs of ASD in early infancy, whereas other children exhibit these signs at age of two or three years (Geschwind & Levitt, 2007). Each child with ASD has a different constellation of symptoms and abilities as well as functional impairments that vary in terms of severity - therefore, their support needs may range from none to substantial (Public Health Agency of Canada, 2008; National Academies of Sciences, Engineering, and Medicine, 2015). Additionally, there are heterogeneities in treatment responsiveness and developmental trajectories of children with ASD – two children can function similarly at the same age however show different developmental outcomes in future years (Geschwind & Levitt, 2007). A wide variety of medical disorders in areas such as immunology, neurology, psychiatry, and gastroenterology have been observed among children with ASD (Muskens, Velders, & Staal, 2017; Simonoff et al., 2008). Considering the functional impairments, treatment responsiveness, and comorbidities that children with ASD experience is important for informing treatment and care strategies based on their needs (Muskens et al., 2017).

Given the range and complexity of the associated medical issues, children with ASD and their families interact with a wide variety of health care professionals in different capacities (Anagnostou et al., 2014). Anagnostou et al. (2014) found that due to the diverse impairments associated with ASD, a variety of behavioural intervention approaches have been developed. The most common behavioural therapy includes applied behaviour analysis (ABA) techniques, based on the antecedent-behaviour-consequence contingency learning principles, that are implemented through a variety of strategies that teach skills and reduce problem behaviour in children with ASD

(Anagnostou et al., 2014). There is strong empirical support for the effectiveness of ABA based techniques (Waters, Amerine Dickens, Thurston, Lu, & Smith, 2018). Recent reviews of the literature suggest that participation in Early Intensive Behavioural Intervention (EIBI), an ABA based technique, improves adaptive behaviour, communication, daily living skills, and socialization capabilities among children with ASD (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Eldevik, Hastings, Jahr, & Hughes, 2012). Earlier intervention for these children is better for their development, including improving behavioural and cognitive outcomes (McConachie & Diggle, 2007; Janus et al., 2018). Moreover, children who are completely non-verbal but begin intervention in the pre-school years are more likely to become verbal than children who begin intervention after they turn 5 years old (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). There is consensus that it is best to begin intervention at the earliest time possible, as the “wait and see” approach for early intervention of ASD can have significant negative consequences for children with this disorder (Koegel et al., 2014).

ASD is also associated with salient financial and personal costs to families and society (Zwaigenbaum, 2010). Families of children with ASD are more likely to have financial challenges, spend significant amount of time providing care for their children, and stop or reduce work compared to families of children with other special needs (Lord et al., 2000). Families of children with ASD may need to seek services from speech therapists, occupational therapists, and psychologists, as well as incur out of pocket expenses for special equipment or diet (Dudley & Emery, 2014). While the overall economic costs of providing care to children with ASD is not yet well established in

Canada, estimates from 2003 suggest the annual EIBI costs range between \$40,000 to \$75,000 per child, depending on several factors including number of treatment hours provided, administrative costs, and training (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006). Furthermore, it has been found that if a child with ASD has severe impairments and requires constant and lifelong supports, the value of caregiver time required to support that individual is approximately \$5.5 million higher compared to someone without ASD (Dudley & Emery, 2014). The economic impact of ASD further highlights the importance of identifying children affected by this disorder and offering intervention earlier in life.

An early diagnosis of ASD is important because it can help children and their families access services, including early intervention which is crucial for supporting their development (Al-Qabandi, Gorter, & Rosenbaum, 2011). Despite the critical role of early diagnosis of ASD, children with this disorder are often not diagnosed until 4 years of age or older even though they can be diagnosed reliably by the age of 2 years (Kleinman et al., 2013; Ouellette-Kuntz et al., 2009). In a 2014 US surveillance study, it was found that 58.1% of children with ASD received their first diagnosis after the age of 3 years and the median age of diagnosis among these children was 4.3 years (Baio et al., 2018). Several factors contribute to the average age of diagnosis at 4 years in U.S. and European settings, including the variation of symptom presentation across cases, the ability to observe children interacting in peer groups as there are social and language deficits that can only be observed in these settings, and symptoms that may change and appear infrequently (Anagnostou et al., 2014; Kleinman et al., 2013; Le Couteur, Haden, Hammal, &

McConachie, 2008). Limited range of tools that are targeted towards pre-school aged children also can impede assessment (Le Couteur et al., 2008). Milder symptom severity of ASD, lower socioeconomic status (SES), and initial parental concerns less specific to ASD (e.g., behavioural problems) have been commonly associated with later diagnosis of ASD (Zwaigenbaum et al., 2019). Additional child (e.g., sex), family (e.g., ethnicity), and community/health system (e.g., rural versus urban location of residence) level factors were less commonly associated with age of diagnosis of ASD (Zwaigenbaum et al., 2019). Currently there is a lack of consensus about the most effective strategies for identifying the early signs of ASD among children (Anagnostou et al., 2014; Kleinman et al., 2013). Professional groups such as the Canadian Paediatric Society (CPS) emphasize the importance of developmental surveillance, while considering parents' concerns and observing the child with or without using standardized tools (Anagnostou et al., 2014). The CPS recommends a multistage process of identifying children with ASD, where parents and community professionals contribute to the identification of red flags of this disorder, which leads to referrals for developmental assessments by community physicians or other care providers.

## **1.2 Prevalence of children with ASD**

The prevalence of ASD has been increasing worldwide in recent decades, accompanied by considerable debate regarding factors driving this increase (Pérez-Crespo et al., 2019). Changes in diagnostic criteria over time, emergence of new assessment instruments, inaccurate diagnosis, using different methodologies to determine prevalence estimates, as well as increased awareness about ASD are considered factors that may

contribute to the increase in prevalence of this disorder (Matson & Kozlowski, 2011). In the U.S., the prevalence of children with ASD has been rising since the 1990s (Christensen et al., 2018). In Canada, longitudinal data on prevalence of children with ASD are not available for all provinces and territories. However, data collected through 2008 in Newfoundland and Labrador and 2010 in Prince Edward Island and Southeastern Ontario show average annual percent increases in prevalence ranged from 9.7% to 14.6% (Ouellette-Kuntz et al., 2014). In both U.S. and Canada, regional differences in age at diagnosis of ASD have been identified (Coo et al., 2012; Mandell, Novak, & Zubritsky, 2005). In Canada, significant inter-regional differences in age at diagnosis of ASD have been observed in Manitoba, Southeastern Ontario, Prince Edward Island, and Newfoundland and Labrador – the median age at diagnosis was highest in Southeastern Ontario (4.6 years) (Ouellette-Kuntz et al., 2009). Findings of a recent Canadian study showed that province of residence accounted for 4% of variance in age of diagnosis, independent of the child's developmental skills and ASD symptoms (Zwaigenbaum et al., 2019).

The pathways for identifying children with ASD vary across the provinces and territories in Canada. For example, for the case of Ontario, during the well-baby and well-child visits for infants and children from 1 week to 5 years of age, including the enhanced 18-month well-baby visit, which was introduced in 2009, general practitioners and pediatricians assess the child's development and make referrals for specialized assessments if it's determined that the child is not meeting developmental milestones (Rourke, Leduc, & Rourke, 2017; Guttman, Cairney, MacCon, & Kumar, 2016).



Additionally, these primary care providers can monitor and address parental concerns at regular visits about the child's development, which can further lead to referrals to specialized assessments such as vision and hearing assessments if necessary. Once the specialized assessments are completed, the child may be referred to a variety of specialists including general pediatricians, developmental pediatricians, psychiatrists, and neurologists, who not only confirm (or not) a diagnosis of ASD, but also evaluate medical comorbidities.

Depending on the resources available, such as the range and number of health care professionals accredited to provide diagnosis, number of advocacy organizations, and regional spending on ASD services, the age at which children receive their diagnosis can vary across systems and jurisdictions (Mazumdar, Winter, Liu, & Bearman, 2013). This can lead to geographic differences in the age of diagnosis of ASD, where areas with more resources can have a higher prevalence of children with this disorder. It has been proposed that presence of “diagnostic clusters” should be positively associated with availability of community resources (Mazumdar et al., 2013). However, this association and the mechanisms underlying it have not been studied extensively.

### **1.3 Development of children with ASD**

While there has been much research focusing on factors that influence the occurrence of ASD, there has been a lack of research examining factors that influence development of children with this disorder. Differences in developmental health of children with ASD have been observed depending on time of diagnosis (Janus et al.,

2018; Landa, Gross, Stuart, & Faherty, 2013). Children with ASD diagnosed late (by Grade 3) had consistently higher scores than children with this disorder who were diagnosed early (by kindergarten) in five areas of development measured in kindergarten, where higher scores reflect better functioning in these areas: physical, social, emotional, language/cognitive, and communication/general knowledge (Janus et al., 2018). A study by Fountain et al. (2012) showed children with ASD who are high functioning in early years tend to improve more rapidly over time in social and communication functioning. This study showed that children with this disorder who are low functioning in early years can also improve substantially in social and communication functioning by adolescent years to match outcomes comparable to high functioning children. These children with ASD who are low functioning in early years, who have been identified as “bloomers”, are those without intellectual disability and those with non-minority and more educated mothers. Although the mechanisms through which SES factors influence developmental trajectory outcomes have not been identified, some of the intervening factors that have been proposed are home and neighbourhood environments, as well as the effectiveness with which parents are able to advocate for their children (Fountain et al., 2012).

A review by Williams et al. (2007) shows that children with ASD experience direct and indirect consequences of social interaction deficits. They found social skill deficits in youth with ASD have been associated with academic and occupational under-achievement. It has also been proposed that social skill deficits may contribute to mood and anxiety problems in later development (Williams, Keonig, & Scahill, 2007). Adaptive behaviours, which include age-appropriate behaviours needed for individuals to live

independently and complete tasks of daily living appropriately, are usually found to be lower than expected in children with ASD for their intellectual level – this discrepancy increases as children get older (Baghdadli et al., 2012). Furthermore, motor skill delays not only are present early in children with ASD, but they also become greater as children age – exemplifying the breadth of developmental challenges children experience throughout their life (MacDonald, Hatfield, & Twardzik, 2017).

#### **1.4 Ecology of child development**

Children are subject to a wide variety of developmental forces as they grow up, which influence their developmental trajectory (Bronfenbrenner, 1977). Bronfenbrenner's ecological systems theory proposes a dynamic model where children are situated within broader environments that shape them and are shaped by them. This model consists of several nested systems, starting with an individual's immediate environments, such as the family home and neighbourhood (microsystem), the interactions between these immediate environments (mesosystem), formal and informal social structures that influence people and their environments (exosystem), as well as the cultural backdrop on which these three systems develop (macrosystem). Recently, Bronfenbrenner added 'chronosystem' to the model, which encompasses the changes or consistency in a person's characteristics and the environment where they live over time (Shelton, 2019). As it will be described below, SES can operate through this dynamic model in different environments to influence health of children.

## **1.5 Socioeconomic gradients in health**

Socioeconomic status has been identified as a significant determinant of health. While different ways of measuring SES have been proposed, the most common measures include quantification of family income, parental education, as well as occupational status (Bradley & Corwyn, 2002). In terms of its relationship to health outcomes, SES influences an individual's or group's access to basic resources needed to achieve and maintain good health (Shavers, 2007). The pathways through which SES impacts health include its association with healthcare, environmental exposure, health behaviour and lifestyle (Shavers, 2007).

According to Bronfenbrenner's ecological systems theory, the relationship between SES and health can occur at different levels (i.e. the individual, family, and neighbourhood), where a broad range of mediators at each of these different levels facilitate this relationship (Schreier & Chen, 2013; Bradley & Corwyn, 2002). Specifically, there are physical and social exposures pertaining to SES that operate at both lower (i.e. individual) and higher (i.e. family and neighbourhood) levels to influence health. Aspects of the physical environment at the family and neighbourhood levels include presence or absence of physical components of the environment that can influence health, such as traffic, parks, and allergens. Aspects of the social environment at these higher levels that can influence health have their origin in the interactions between people or their psychological perceptions of their environment, such as violence, social capital, or characteristics of people, such as parenting styles. Physical and social exposures at the individual, family, and neighbourhood levels can independently

influence health. However, it is important to note that physical and social exposures at different levels can also interact with each other in dynamic ways to alter their impact on health. Synergistic relationships can occur between physical and social exposures within each level and they do not function independently of one another. For example, the amount of resources available to a family can influence the level of violence present in the family and affect a child's health accordingly. Furthermore, physical and social exposures from different levels can also influence each other to alter health outcomes. As an instance of a unidirectional influence, neighbourhood characteristics can alter family characteristics which in turn can have implications for a child's health. As an example of a bidirectional and reciprocal influence, family dynamics can influence a child's psychological state, and vice versa, which can shape a child's health as well. Furthermore, the relationship between SES and health can remain constant or change as characteristics of individuals, families, and neighbourhoods stay the same or evolve over time.

There is substantial evidence indicating the strong relationship between SES and health, with health status being unevenly distributed across SES (Fiscella & Williams, 2004). The disparities in health across SES are referred to as the socioeconomic gradient, highlighting the fact that change in health outcomes is gradual and occurs across the full spectrum of SES (Syme & Berkman, 1976). While effects are largest for those living in poverty, gradients in health disparities are observed across the SES spectrum (Fiscella & Williams, 2004). It has been repeatedly observed that lower SES is associated with higher morbidity, mortality, and disability rates for almost every disease and illness, and these

differentials have not been diminished over time (Syme & Berkman, 1976; Roberts & Power, 1996). On the other hand, higher SES is associated with significant benefits to health (Schreier & Chen, 2013). It has been found that children from families with lower income and with mothers with lower levels of education have worse health on average compared to children from higher SES backgrounds, a gradient that also steepened with age (Allin & Stabile, 2012). However, there is also evidence indicating that SES gradients that are present in earlier childhood flatten or disappear by adolescence – which has been attributed to the greater influence of secondary school, peer group, and youth culture over family background as children grow older (Sepehri & Guliani, 2015).

### **1.6 Children with special needs and SES**

Examining the impact of SES on health of children with special needs is particularly important for several reasons. Findings from Statistics Canada's Participation and Activity Limitations Survey (PALS) show that families of children with special needs are more likely than families of healthy 4-year-olds to have household incomes below the Low Income Cut-Off (25.3% vs. 19.7%) (Fawcett, & Roberts, 2003). Findings from the PALS also show that family assistance, out-of-pocket expenses, needing but not receiving health services from a social worker, condition of the dwelling, as well as residential location are associated with the severity of developmental disabilities observed among children (Raouafi, Achiche, & Raison, 2018). The SES of children with special needs also has important implications for children's access to special education programs as well as their school achievement. In the U.S., it has been found that rates of participation in special education are higher in states where income inequality is lower compared to states

with higher income inequality (Newschaffer et al., 2007). Additionally, socioeconomic advantage has been positively associated with higher parental involvement in the academic work of their children with developmental disabilities (Szumski & Karwowski, 2012). Moreover, socioeconomic disadvantage has been associated with increased risk of conduct disorder, emotional disorder, low social skills, as well as externalizing behaviour problems among children with developmental disabilities, all of which can impact the school readiness and academic success of these children (Webster-Stratton, Jamila, & Stoolmiller, 2008; Cybele, 2003; Emerson & Hatton, 2007; Szatmari et al., 2009).

Given the increased likelihood of children with special needs to be from low-income families, as well as the complex health challenges experienced by these children, it is possible that SES gradients may operate differently among this sub-group of children. While there have been some studies examining the relationship between SES with prevalence of children with special needs, including children with ASD, or relationship between SES and health outcomes in this population, few if any studies examined both prevalence of specific disorders and their health outcomes in relation to SES in the same study (Zeraatkar et al., 2020). However, examining these associations at the population level is crucial for planning policies and programs that aim to decrease the socioeconomic disparities in health between typically developing children and children with special needs.

## **1.7 Neighbourhood influence on health**

There is growing consensus that population inequalities in health outcomes are usually not fully accounted for by combinations of individual factors and may therefore be attributable to factors that operate at an aggregate level (Pickett & Pearl, 2001). It has been proposed that contextual factors, such as characteristics of neighbourhoods, may be the most important determinants of health of a population – which is manifested through the constant interaction between humans and their environment (Pickett & Pearl, 2001; Winkelstein, 1972). Neighbourhoods where people live can impact their health through a variety of mechanisms, including the availability and accessibility to health services, infrastructure deprivation (such as lack of parks, stores selling food at affordable prices), the prevalence of dominant attitudes regarding health and health related behaviours, as well as the lack of social support. Neighbourhood deprivation is a feature of the neighbourhood environment, which is commonly defined by the proportion of residents with low SES, low education, unemployed people and/or people receiving welfare assistance (Li, Sjostedt, Sundquist, Zoller, & Sundquist, 2014; Lang, Llewellyn, Langa, Wallace, Huppert, & Melzer, 2008). Household income is typically geographically clustered, resulting in neighbourhoods with different levels of socioeconomic deprivation (Emerson, 2012). Given the significant role of place of residence in influencing health, examining the impact of neighbourhood deprivation on children's health can help inform the development of customized early interventions according to areas of need.

There is growing evidence on the relationship between neighbourhood deprivation and health of typically developing children. It has been found that a significant



relationship exists between neighbourhood deprivation and physical and mental health of children who reside there (McCulloch, 2006; Sellstrom & Bremberg, 2006).

Neighbourhood deprivation has a negative impact on children's body mass index scores and waist circumference, as well as increases the risk of asthma (Noonan, Boddy, Knowles, & Fairclough, 2016; Simons, Dell, Moineddin, & To, 2019). Neighbourhood deprivation also has a negative impact on children's prosocial behaviour and is associated with increased risk of emotional and behavioural problems (Safra et al., 2016; Caspi, Taylor, Moffitt, & Plomin, 2000; Kalff et al., 2001). Current literature suggests that neighbourhood-level deprivation may have a greater impact on children's cognitive development compared to effects attributed to rates of household-level deprivation (McCulloch, 2006). Even after controlling for child- and family-level characteristics, living in low-income neighbourhoods has negative impact on children's school readiness and academic achievement, and is associated with higher rates of externalizing behaviour problems (McCulloch, 2006). However, there are also studies from the U.S. and Europe that show that neighbourhood SES has nonsignificant or trivial effects on health of children (Solon, Paige, & Duncan, 2000; Kauppinen, 2007). It has been suggested that lack of significance of neighbourhood effects observed in these studies may say more about the unique geographic context in which the studies were conducted, or the strong impact of family effects (Solon et al., 2000; Kauppinen, 2007). While these studies do not dispute the validity of neighbourhood effects, they do highlight that neighbourhood effects on health outcomes may not be generalizable across settings – hence the importance of examining them in the setting of interest for service planning.

## **1.8 Children with ASD and SES**

Despite the increasing prevalence of children with ASD and the significant influence of SES on health, knowledge of the relationship between SES and health of children with this disorder remains limited. There is mixed evidence regarding the association between individual-level SES and prevalence of ASD. While some studies have reported higher prevalence of children with ASD among higher-SES families, other studies have not observed this association (Delobel-Ayoub et al., 2015; Bhasin & Schendel, 2007). Additionally, an excess risk of ASD among children from lower-SES families has also been observed in several studies (Bhasin & Schendel, 2007; Emerson, 2012). It has been proposed that ASD occurs uniformly across the socioeconomic gradient once social class bias in case detection is eliminated, where an increased prevalence is observed among those with higher access to diagnostic services (Delobel-Ayoub et al., 2015; Bhasin & Schendel, 2007). There is some support for this hypothesis – it has been shown in the U.S. that SES-ASD associations vary depending on the source used to measure prevalence and no association is observed when school data sources are used to identify cases (Bhasin & Schendel, 2007). The differences in SES-ASD associations have also been attributed to differential awareness by parents and providers in different settings, possibly differential application of diagnostic criteria depending on location, and varying measures of social class (Delobel-Ayoub et al., 2015; Bhasin & Schendel, 2007; Thomas et al., 2012).

Thus far, few studies have explored the relationship between neighbourhood deprivation and ASD and their results are inconsistent (Li et al., 2014). Some studies have

reported higher prevalence of children with ASD among higher-SES neighbourhoods, while other studies have reported that ASD is more prevalent in lower-SES neighbourhoods (Emerson, 2012; Thomas et al., 2012; Hock & Ahmedani, 2012).

However, the relationship between SES – both at the individual and neighbourhood level – with development of children with ASD remains largely unexplored. Considering the significant impact of socioeconomic disadvantage on the health outcomes of typically developing children, it is important to examine whether children with ASD are also impacted in a similar fashion to help inform early intervention service planning.

Understanding the relationship between neighbourhood SES and development of children with ASD, while controlling for individual SES, is particularly important as it will help identify the independent impact of place of residence on health of children with this disorder. Children with ASD often require individualized interventions, the availability of which can be determined by neighbourhood SES itself. Given the heterogenous nature of ASD, determining the influence of contextual factors such as neighbourhood SES on children's development can facilitate service planning to serve groups of children – presenting a pragmatic approach to support health of children with ASD.

### **1.9 Focus of Dissertation**

In recent years, while the research focusing on children with ASD and factors that influence their health has been increasing, there has been a paucity of research on this sub-population of children from a national perspective. Although the National Autism Spectrum Disorder Surveillance System provides the prevalence of children with ASD living in some provinces and territories in Canada for 2015, our knowledge of

neighbourhood level prevalence of kindergarten children with this disorder as well as their development across all the provinces and territories remains limited (Public Health Agency of Canada, 2018). Examining the prevalence and development of kindergarten children with ASD at the neighbourhood level that represents a meaningful geographic unit of residence has particular value. There is growing evidence indicating that kindergarten children's health is influenced by neighbourhood characteristics (Kohen, Oliver, & Pierre, 2009; Curtis, Dooley, & Phipps, 2004; Minh, Muhajarine, Janus, Brownell, & Guhn, 2017). In this context, identifying jurisdictional differences in prevalence and development of children with ASD based on the neighbourhoods where they live can allow the implementation of early intervention strategies in a more targeted manner. Knowing the types of neighbourhoods where children with ASD are spatially clustered, as well as the relationship between neighbourhood SES and development of these children, can allow the number and nature of intervention strategies to be adapted based on needs observed in different neighbourhoods.

One of the most critical factors that can determine the future development of children with ASD is the age at which they receive the diagnosis. The earlier this happens, the more likely children are to access services necessary to support their development. While factors that operate at individual and aggregate levels that influence the age of diagnosis of ASD have been explored in other countries, similar research has been sparse in Canada. Understanding the relationship between characteristics of children with ASD and their primary care providers can help determine opportunities to facilitate earlier diagnosis of this disorder. Examining this relationship can help identify

populations and areas in need and inform policy-level decision making regarding the type and location of services to offer, thereby lowering the age of diagnosis of this disorder (Frenette et al., 2013).

The overall goal of this dissertation is to examine the impact of social determinants on health of children with ASD. This is achieved through three papers that are informed by Bronfenbrenner's ecological systems theory, which considers the direct and indirect effects of different contexts on children's health, as well as the bidirectional interactions that exist between the child and the child's social networks (Bronfenbrenner, 1977). These contexts include family and neighbourhood influences and their combined effects on children's health. The significance of the combined effects of these contexts lies in the uniqueness of these contexts, thus their collective effect on the health of children with ASD is more important in predicting their health outcomes than each context alone. Given the cross-sectional nature of the research for this dissertation, the chronosystem from Bronfenbrenner's model was not considered.

The first and the second papers in this thesis are pan-Canadian in scope. The first paper examines the prevalence and developmental health of children with ASD at the neighbourhood level. The second paper examines the relationship between neighbourhood SES and developmental health of children with ASD. Using Ontario as a case study province, the third paper examines the relationship between characteristics of children with ASD and their primary care providers with age at first diagnosis of this disorder. Collectively, findings of this dissertation contribute to the literature by exploring the neighbourhood clustering of children with ASD and relationship between neighbourhood

SES with development of children with this disorder in Canada, as well as factors that influence the age of diagnosis in Ontario. Chapters Two, Three, and Four present each of the three papers of this thesis, respectively. Chapter Five presents a discussion of findings from the three papers, as well as highlights the policy and future research implications of these findings.

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**Chapter Two: Neighbourhood-level prevalence of teacher-reported Autism Spectrum Disorder among kindergarten children in Canada: A population level study**

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### **Abstract**

Growing evidence indicates that young children's health, including those with special health needs, is influenced by neighbourhood characteristics. The objectives of this study are to determine, among Canadian kindergarten children (1) the variability in prevalence of ASD at the neighbourhood level; (2) the prevalence of neighbourhoods with no children with ASD; (3) the prevalence of neighbourhoods with different levels of spatial clusters of children with ASD; and (4) the developmental health status of children living in neighbourhoods with no children with ASD and different levels of spatial clusters of children with this disorder across provinces and territories. This study used data from a population level database of child development in kindergarten, collected with the Early Development Instrument (EDI). The EDI is completed by kindergarten teachers, includes records of medical diagnoses, and has been administered at the population level in most Canadian provinces and territories. Descriptive statistics were used to examine prevalence and development of children with ASD at the neighbourhood level. Across provinces and territories, the number of children with ASD per neighbourhood ranged from none (in 21.1 % of neighbourhoods) to 21. Jurisdictional patterns of average concentration of children with ASD per neighbourhood were aligned with the average age of diagnosis, that is the highest clustering was observed where the age of diagnosis was earliest, and lowest when it was latest. There was no consistency in children's developmental vulnerabilities among neighbourhoods with low- and high-level clustering of children with ASD, suggesting first, that clustering levels may not be a

reliable indication of need of early intervention services, and second, that there is a marked heterogeneity in the development of children with ASD.

Key words: ASD, kindergarten, developmental disabilities, behaviour, Early Development Instrument, neighbourhood

## **1. Introduction**

Autism Spectrum Disorder (ASD) is a commonly diagnosed neurodevelopmental disorder in Canada, with a national prevalence estimate of 1 per 66 children diagnosed in 2015 (Public Health Agency of Canada, 2018). ASD is a heterogeneous, behaviourally-defined neurodevelopmental disorder, which has been associated with multiple genetic conditions, but it has no unifying pathological or neurobiological etiology (Geschwind & Levitt, 2007). According to the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM – 5), the core dysfunctions of ASD occur in two behavioural domains: difficulties in social communication and social interaction, as well as restricted, repetitive behaviours and interests (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). The characteristics and varying severity of ASD are now more widely recognized – thus, the diagnosis rate of this disorder has increased substantially over the years (McConachie & Diggle, 2007).

Children with ASD have heterogeneous developmental trajectories (Fountain, Winter, & Bearman, 2012). Children who are high functioning in early years tend to improve in their development more rapidly over time (Fountain et al., 2012). However, even children who are very low functioning in childhood through middle years can also improve in their development substantially by adolescence to match outcomes comparable to high functioning children (Fountain et al., 2012). Research suggests that participation in Early Intensive Behavioural Intervention (EIBI) improves adaptive behaviour, communication, daily living skills, and socialization capabilities among children with ASD (Eldevik, Hastings, Jahr, & Hughes, 2012; Peters-Scheffer, Didden,

Korzilius, & Sturmey, 2011). There is evidence indicating that earlier intervention for these children is better for their development, including improving behavioural and cognitive outcomes (Janus et al., 2018; McConachie & Diggle, 2007).

While several studies have demonstrated that ASD can be reliably diagnosed by the age of 2 years, the median age of ASD diagnosis remains over age of 4 years (Janus et al., 2018; Monteiro et al., 2015). Thus, the identification of ASD among kindergarten children between the age of 4 to 6 years presents an optimal opportunity to target early interventions (Janus et al., 2018). Although epidemiological studies suggest that the prevalence of ASD is increasing, there are several challenges associated with the current methods available for estimating prevalence (Matson & Kozlowski, 2011; Rice et al., 2010). Estimates based on administrative databases (which depend on special education classifications, ASD service eligibility, or medical billing codes) have several limitations (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). For example, they may underestimate prevalence among specific subpopulations who have reduced access to systems that generate administrative counts and therefore are not captured in these counts – leading to socioeconomic disparities in the prevalence of ASD (Zablotsky et al., 2015). Furthermore, criteria for special education or other ASD services can differ across jurisdictions (Zablotsky et al., 2015). Survey-based estimations also have limitations – including respondents’ lack of fluency to respond in the dominant language, general population surveys not being designed to include sufficient numbers of individuals affected by rare conditions precluding analyses that will generate reliable estimates for these sub-populations, reliance on respondents’ ability to understand the questions asked

and accurately recall the specific diagnosis assigned (Ouellette-Kuntz et al., 2012; Zablotsky et al., 2015). Determining the prevalence of ASD using multiple data sources remains a difficult task given different data maintenance and linkage procedures across systems and jurisdictions.

In the Canadian context, the Early Development Instrument (EDI), a population-based developmental assessment tool, presents a unique opportunity to monitor the prevalence and developmental health of kindergarten-age children with ASD (Janus & Offord, 2007). The EDI is implemented across Canada and is completed by teachers for each child in kindergarten classes. It provides data on development in five domains: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge. While the EDI is completed for individual children, the data obtained are interpreted at different levels of aggregation (e.g. children attending a school, children living in a neighbourhood) to provide information on the strengths and weaknesses of children in a particular group/community. Given the wide-scale implementation, the EDI data provide valuable information on low-frequency populations such as children with special needs, who typically represent a small percentage of population at the community level (Janus et al., 2018).

Although the National Autism Spectrum Disorder Surveillance System provides the prevalence of children with ASD living in some provinces and territories in Canada for 2015, including Newfoundland and Labrador, Prince Edward Island, Quebec, British Columbia, Nova Scotia, New Brunswick, and Yukon, our knowledge of prevalence of

kindergarten children with this disorder in other provinces and territories, as well as the development of these kindergarten children across all provinces and territories remains limited (Public Health Agency of Canada, 2018). Examining the prevalence and development of kindergarten children with ASD at the neighbourhood level that represents a meaningful geographic unit of residence has particular value. There is growing evidence indicating that kindergarten children's health is influenced by neighbourhood characteristics (Curtis, Dooley, & Phipps, 2004; Kohen, Oliver, & Pierre, 2009; Minh, Muhajarine, Janus, Brownell, & Guhn, 2017). Furthermore, there is increasing consensus that inequalities in health outcomes of a population are usually not fully accounted for by combinations of individual level factors and may therefore be attributable to factors that operate at an aggregate level, such as the neighbourhood level (Pickett & Pearl, 2001). Pickett and Pearl (2001) noted that contextual factors may be the most important determinants of the health of a population. There is no consistency in literature regarding the association between neighbourhood socioeconomic status and prevalence of children with ASD (Emerson, 2012; Hock & Ahmedani, 2012; Li, Sjostedt, Sundquist, Zoller, & Sundquist, 2014; Thomas et al., 2012). In contrast, spatial clustering of children with ASD appears to be associated with neighbourhood resources that can facilitate diagnosis – including number of pediatricians, number of advocacy organizations, and regional center spending on ASD services (Mazumdar, Winter, Liu, & Bearman, 2013). Children who live in close proximity of other children previously diagnosed with ASD are more likely to be diagnosed with ASD as well – which has been attributed to the diffusion of information about ASD through social networks, a

phenomenon that can lead to spatial clustering of children with ASD in neighbourhoods (Liu, King, & Bearman, 2010). In view of these findings, it is propitious to examine the prevalence of ASD, and the development of all children living in neighbourhoods with different levels of spatial clusters as this will allow to generate hypotheses about drivers of prevalence of ASD and its association with child development. Furthermore, identifying geographic and jurisdictional differences in the prevalence of ASD is integral for providing necessary early intervention services and community education in areas of need. Combination of availability of reliable developmental outcomes at a national, population level for kindergarten children with spatial and diagnostic information makes this task particularly promising.

The objectives of this study are to determine, among kindergarten children across provinces and territories in Canada (1) the variability in prevalence of ASD at the neighbourhood level; (2) the prevalence of neighbourhoods with no children with ASD; (3) the prevalence of neighbourhoods with different levels of spatial clusters of children with ASD; and (4) the developmental health status of children living in neighbourhoods with no children with ASD in comparison to children living in neighbourhoods with different levels of spatial clusters of children with ASD.

## **2. Methods**

### ***2.1 Kindergarten in Canada***

Depending on the province or territory in Canada, children may start kindergarten at the age of 4 to 5 years. In Ontario, children can begin school in September of the

calendar year they turn 4 years old, called “Junior Kindergarten”. However, the majority of children in Canada begin school in the fall of the year they turn five, called “Senior Kindergarten”. In this study, only data collected at the Senior Kindergarten level are used. Junior Kindergarten is universally implemented in only one province in this study (Ontario), therefore variable identifying participation in this level was excluded from this study.

## ***2.2 Early Development Instrument***

To determine the prevalence and developmental vulnerability of kindergarten children with and without ASD at the neighbourhood level, this study used data from the population-wide database of child development in kindergarten, collected using the EDI. The EDI has been administered at the population level in most Canadian provinces and territories since 2004 (Janus & Offord, 2007). The EDI is a measure of developmental health, a concept encompassing cognitive, social and behavioural development (Keating & Hertzman 1999), completed by teachers for children aged 4-6 years who are in their second term of senior kindergarten. It contains 103 items covering five broad domains of developmental health: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge. The EDI also includes a number of demographic questions, including child’s date of birth, gender, first language, and “English or French as a Second Language Status” (E/FSL), which indicates a child’s lack of fluency in the school’s language of instruction, and postal code of child’s residence. The psychometric properties and validity of the EDI have been reported in many studies, as well as associations with other



developmental outcomes (Guhn et al., 2016; Janus et al., 2007; Janus & Offord, 2007). The EDI results are routinely used for monitoring and reporting on child development status at jurisdictional and geographic, community levels.

The questions on the EDI are answered on the dichotomous scale (yes/no: 0=yes, 1=no), or a Likert scale (e.g., Never/not true=0, Sometimes/somewhat true=5, Often/very true=10). To determine the overall score for a domain or subdomain, the responses are summed and divided by the number of questions with valid answers. The scores are not validated for a clinical/diagnostic use. The scale is referenced to a normative baseline, where scores below the 10<sup>th</sup> percent cut-off indicate vulnerability on a domain, and vulnerability on one or more domains indicates overall vulnerability (Janus & Duku, 2007).

The EDI also includes teacher report on any health diagnosis the child may have, if they are aware “based on parent or health provider report”. These items have been included on the EDI since the 2009/10 school year and include a list of over 30 most frequent childhood diagnoses (Janus et al., 2018). The ASD is one of these diagnoses, and evidence indicates at least a fair concordance between the EDI-based prevalence with other data sources in two provinces (Reid-Westoby, Horner, & Janus, 2018). The data used in this study comes from the database created for the Canadian Children’s Health in Context Study (Janus et al., 2018a).

### ***2.3 Defining geographic neighbourhood boundaries***

Discrete neighbourhoods were created to analyze the EDI data, using a detailed set of criteria (Guhn et al., 2016). Neighbourhood boundaries were established to reflect geographic and socioeconomic diversity across neighbourhoods. Neighbourhood boundaries were defined using the following criteria: must have a minimum of 50 EDI records; results should be verified with local contacts, where possible; should not have more than 400-600 EDI records per unit; must be located within Statistics Canada Census Divisions (these are a group of neighbouring municipalities joined together for regional planning and managing common services, representing intermediate geographic areas between the province/territory level and the municipality (census subdivision)); should use local ‘neighbourhood’ or other applicable boundaries if possible; spatial units must be made up of dissemination blocks (DBs) (these are the smallest geographic areas covering the entire territory of Canada – where the area of each DB is equal to a city block that is bounded by intersecting streets). If a neighbourhood had more than 400-600 EDI records, it was further divided to display variance across spatial units, while prioritizing any pre-existing neighbourhood boundaries. As long as large rural areas included a minimum of 50 EDI records, they were included as individual units using Canada Census subdivisions, which are widely used as a proxy for rural municipality boundaries across the country. If EDI record density was low, Census subdivisions were used as the largest spatial unit. Each neighbourhood has been assigned with a unique name and a label.

## ***2.4 Procedure***

### ***2.4.1 Sample***

This study used EDI data on Senior Kindergarten (SK) children that teachers provided in school years 2010/11, 2011/12, 2012/13, 2013/14, and 2014/15. There were multiple implementations of the EDI in some provinces and territories over time during this study period (Janus et al., 2018a; Table 1). There were 5804 children with ASD, representing 1% of the children with available EDI records. New Brunswick, Prince Edward Island, and Nunavut were excluded from the study sample, as EDI data were not collected in these provinces during the study period. Children with ASD included in this study also had the following comorbidities: mental health disorders (1.6%), speech/language disorders (2.7%), sensory and motor disorders (1.3%), and other disorders (1.2%). Please note: since only kindergarten children are included in the sample, to simplify the language they will be sometimes referred to in Methods and Results only as “children”.

### ***2.4.2 Analyses***

In order to determine prevalence of children with ASD at the neighbourhood level, the number of children with this disorder in a neighbourhood was measured. This was done to enhance the interpretability of the results, as the proportion of children with ASD among all kindergarten children in a neighbourhood was anticipated to be very small. While the number of kindergarten children with ASD may be higher in neighbourhoods that are more densely populated, a proportional representation of these

children in a neighbourhood was not considered appropriate given the low-frequency of this population.

Descriptive statistics, including frequencies, percentages, means and standard deviations, were used to address the objectives of this study. This included examining the prevalence of children with ASD at the neighbourhood level, the prevalence of neighbourhoods without children with ASD (these neighbourhoods included typically developing kindergarten children as well as those with other medical diagnoses), and the prevalence of neighbourhoods with different levels of spatial clusters of children with ASD (these neighbourhoods included typically developing children, children with ASD, as well as those with other medical diagnoses). In order to examine spatial clusters, neighbourhoods were categorized according to their number, ranging from neighbourhoods with one child with ASD to neighbourhoods with two, three, four, five, and six or more. Neighbourhoods with one to five children with ASD were considered to have low level clustering and those with six or more were considered to have high level clustering. Further, descriptive statistics were used to examine the developmental vulnerability of all children living in neighbourhoods with no children with ASD in comparison to the vulnerability of children living in neighbourhoods with increasing levels of spatial clusters of children with ASD across provinces and territories in Canada.

### ***2.4.3 Ethics***

Ethics approval for this study was obtained from the Hamilton Integrated Research Ethics Board.

### **3. Theory**

This study was informed by the “ecological model” of child development proposed by Bronfenbrenner, which highlights that there are many levels of influence on child development: individual, neighbourhood, regional, and jurisdictional (Adler et al., 1994; Hertzman, 1999). This study attempted to quantify the relationship between children’s development and the neighbourhood where they live, by categorizing neighbourhoods according to the number of kindergarten children with ASD – which was expected to have differential impact on children’s health. This represents an important contribution to the literature, as few studies have used the ecological model to study health of children with special needs thus far. Those that have, tend to focus on physical rather than mental disorders (e.g., Ben-David & Nel, 2013; Greenwood, Carta, & Atwater, 1991; Houtrow et al., 2012).

### **4. Results**

Across Canada, there were 419 (21.1%) neighbourhoods without children with ASD and 1544 (78.6%) neighbourhoods with children with ASD. The demographic characteristics of neighbourhoods without children with ASD and with different levels of spatial clusters of children with ASD per neighbourhood are presented in Appendix A. In the majority of provinces and territories, the average age of children was 5.7 years and close to 50% of the children were male, regardless whether the neighbourhoods had or did not have children with ASD. Among the neighbourhoods without children with ASD, the average proportions of children with EFSL status ranged from 0.4% (in

Newfoundland and Labrador) to 30.8% (in Manitoba). These proportions ranged from 0.8% (in Nova Scotia) to 31.7% (in Quebec) in neighbourhoods with different levels of spatial clusters of children with ASD.

#### ***4.1 Prevalence of children with and without ASD***

At the national level, there were on average 2.89 children with ASD per neighbourhood (Table 2). In all provinces and territories but Northwest Territories, between 10.1% (Ontario) and 40% (Saskatchewan) of neighbourhoods had no children with ASD (Table 3). The minimum number of children with ASD in a neighbourhood (1) was observed in all provinces and territories but Northwest Territories and the maximum (21) was observed in Ontario. The average number of children with ASD in a neighbourhood ranged from 1.26 (in Quebec) to 5.15 (in Newfoundland and Labrador). With the exception of Manitoba, Newfoundland and Labrador, and Nova Scotia, there was a greater proportion of neighbourhoods with three or fewer children with ASD compared to neighbourhoods with four or five children with ASD. The proportion of neighborhoods with six or more children with ASD ranged from 3.3% (in Quebec) to 40.4% (in Nova Scotia).

#### ***4.2 Developmental vulnerability in neighbourhoods without children with ASD***

The average developmental vulnerability of children living in neighbourhoods without children with ASD ranged from 22.4% (in Newfoundland and Labrador) to 40.9% (in Yukon) (Table 4). When vulnerability in specific areas of development was explored, the lowest average proportion of children vulnerable in a neighbourhood was

observed in the Language and Cognitive Development domain in several provinces and territories (Table 4), and the highest in the Emotional Maturity domain and the Communication Skills and General Knowledge domain in most provinces and territories.

#### ***4.3 Developmental vulnerability in neighbourhoods with children with ASD***

Overall, the average developmental vulnerability of children living in neighbourhoods with different levels of spatial clusters of children with ASD varied from 15.3% (in Newfoundland and Labrador) to 45.7% (in Yukon) (Table 5).

In neighbourhoods with one child with ASD, the average proportions of all children who demonstrated overall vulnerability ranged from 19.2% to 47.1%; in neighbourhoods with two children with ASD from 21.4% to 38.7%; in neighbourhoods with three children with ASD from 24.2% to 46.3%; in neighbourhoods with four children with ASD from 20.9% to 45.6%; in neighbourhoods with five children with ASD from 15.3% to 38.2%; and in neighbourhoods with 6 or more children with ASD from 20.6% to 36%.

As the number of children with ASD per neighbourhood increased, the average proportion of all children demonstrating overall vulnerability decreased in Alberta, starting from 32.5% (in neighbourhoods with one child with ASD) and decreasing to 29.4% (in neighbourhoods with six or more), a pattern that was not observed in other provinces and territories (Table 5).

None of the EDI domains showed a consistent pattern of vulnerability in neighbourhoods with each level of spatial cluster of children with ASD across provinces

and territories (Appendices B to F). Neither of the specific spatial clusters showed a consistent pattern of vulnerability in individual EDI domains.

## **5. Discussion**

While there have been some studies examining the prevalence of children with ASD in Canada, including some surveillance studies, to our knowledge, there are no studies that took a national approach in examining the prevalence of kindergarten children with this disorder based on kindergarten teacher report at a neighbourhood level (Ouellette-Kuntz et al., 2014; Public Health Agency of Canada, 2018). Our study found that in most provinces and territories, the number of kindergarten children with ASD per neighbourhood varied from none to as high as 21, as observed in Ontario. The average number of kindergarten children with ASD per neighbourhood ranged from 1.26 (in Quebec) to 5.15 (in Newfoundland and Labrador).

There are several possible explanations for the wide-ranging numbers of kindergarten children with ASD at the neighbourhood level across provinces and territories. Whether these children receive the ASD diagnosis by the time they enter school may be dependent on their province or territory of residence. Geographic variations in case ascertainment is a major factor that contributes to regional disparities in prevalence estimates (Ouellette-Kuntz et al., 2014). One study reported that there were differences in the median age of diagnosis for ASD across four regions of Canada as follows: Newfoundland and Labrador (3.25 years), Prince Edward Island (3.96 years), Manitoba (4 years), and Southeastern Ontario (4.58 years) (Ouellette-Kuntz et al., 2009).



The lowest median age of diagnosis observed in Newfoundland and Labrador complements the results of our study, as the largest average number of kindergarten children with ASD living in a neighbourhood was seen in this province (5.15, see also Table 2). Similarly, the highest median age of diagnosis observed in Southeastern Ontario complements the results of our study, as the average number of kindergarten children with ASD living in a neighbourhood observed in this province (3.82, see also Table 2) was smaller than those observed in three other provinces. In areas where early intervention services are readily available with reduced wait times, there are increased opportunities for earlier diagnosis, which may influence the prevalence estimates of kindergarten children with ASD. For example, there is a “zero” waitlist policy for early intervention for preschool children diagnosed with ASD in Newfoundland and Labrador, whereas the waitlist for these services has been historically long in Ontario, which may influence the ASD diagnosis practices in this province (Gordon, 2012; Ouellette-Kuntz et al., 2009).

Our results show that the level of spatial clustering of kindergarten children with ASD at the neighbourhood level varies across provinces and territories. We found that the proportions of neighbourhoods with no kindergarten children with ASD could be as low as 10.1% (in Ontario) to as high as 40% (in Saskatchewan). Not surprisingly, there were greater proportions of neighbourhoods with three or fewer kindergarten children with ASD compared to those with four or five. We also found the proportion of neighbourhoods with six or more kindergarten children with ASD to be as low as 3.3% (in Quebec) to as high as 40.4% (in Nova Scotia). Considering the positive relationship

between the availability of neighbourhood resources and ASD diagnosis, it is possible that families who are able to do so select to live in neighbourhoods with greater proximity or access to services for children with ASD, which may lead to clustering of children with this disorder (Mazumdar, King, Liu, Zerubavel, & Bearman, 2010). Future study of the resources available in neighbourhoods across Canada may help explain the prevalence profile of kindergarten children with ASD, and the gradient in spatial clustering of kindergarten children with this disorder observed in different provinces and territories.

There is growing evidence regarding the heritability of ASD: several twin studies have suggested that the aggregation of twins with ASD within the same families is best attributed to shared genes rather than shared environment (Chaste & Leboyer, 2012). Having an older biological sibling with ASD has been identified as a significant predictor of the presence of this disorder among younger siblings (Ozonoff et al., 2011). Spatial clustering of kindergarten children with ASD observed in our study may be explained by the presence of families in a neighbourhood with multiple children with ASD, especially in provinces with several years of data, although we were not able to explore this hypothesis further given the lack of relevant family-level information in our study.

Spatial clustering of children with ASD can occur when parents of children exhibiting developmental markers of the disorder and yet not diagnosed with ASD have discussions with parents of children who are diagnosed with ASD, and they learn about symptoms of ASD, how to identify and approach a physician, and how to access and navigate services (Liu, King, & Bearman, 2010). Increased knowledge about ASD may prepare parents to seek diagnosis for their children earlier – which has been defined as the

“cul-du-sac effect” on the diagnosis (Schelly, Jimenez Gonzalez, & Solis, 2018). In this context, the wide-ranging clustering of kindergarten children with ASD observed in our study can also be attributed to the demographic characteristics of the neighbourhoods where they live – there may be a “cul-du-sac effect” on the diagnosis if there are already many children in the neighbourhood with ASD.

Results of a systematic review show that kindergarten children with ASD tend to be less school ready in social-emotional areas than both their typically developing and developmentally delayed peers (Marsh, Spagnol, Grove, & Eapen, 2017), a finding also observed in a previous study using the EDI-measured outcomes (Janus et al., 2018b). Specifically, they tend to have more externalizing behaviours and self-regulation difficulties that influence their school engagement and relationships with their teachers. Longitudinal research on children with ASD indicates significant heterogeneity in developmental pathways from preschool age to early adulthood, demonstrated by much diversity in functioning levels (Fountain, Winter, & Bearman, 2012; Lord, Bishop, & Anderson, 2015; Szatmari et al., 2015). As a neurodevelopmental disorder, it has been proposed that symptoms of ASD likely arise from the complex interaction between the child’s vulnerabilities and their environment (Jones, Gliga, Bedford, Charman, & Johnson, 2014). There is a growing body of literature that have examined factors that influence development of children with ASD operating at individual and aggregate levels, including use of early intervention services, mother’s education level, membership in minority groups, and socioeconomic factors (Eldevik et al., 2012; Fountain et al., 2012; Peters-Scheffer et al., 2011). We found that the average proportion of kindergarten

children with developmental vulnerabilities varied among different levels of spatial clusters of kindergarten children with ASD. However, there appeared to be no systematic association between proportions of developmental vulnerability and the level of spatial cluster of kindergarten children with ASD. Most specifically, on average, the proportions of vulnerability were not lower among kindergarten children living in neighbourhoods with no kindergarten children with ASD.

Higher functioning preschool and kindergarten age children with ASD are more likely to be diagnosed within a spatial cluster than lower functioning children depending on neighbourhood resources available (Mazumdar et al., 2013). According to Mazumdar et al., an increased amount of neighbourhood resources such as number of pediatricians, number of advocacy organizations, regional center spending on ASD services, and socioeconomic status has led to more diagnoses of high-functioning ASD. Spatial clusters of children with less severe ASD can therefore be attributed to diagnostic expansion moderated through the presence of increased neighbourhood resources. Therefore, it was hypothesized that all children living in neighbourhoods with a higher concentration (six or more) of kindergarten children with ASD would be likely to show better developmental health. However, our results do not support this hypothesis: in most provinces and territories, as the number of kindergarten children with ASD per neighbourhood increased, the average proportion of kindergarten children demonstrating overall vulnerability did not decrease, with the exception of Alberta. Neither did we find that vulnerabilities increased with higher levels of clustering. This can be reflective of the fact that even though kindergarten children with ASD are, on average, more vulnerable

than typically developing kindergarten children, this phenomenon is not necessarily true for all kindergarten children with ASD when using the EDI definition of developmental vulnerability, which is based on scores on the instrument. This also speaks to the varying severity of ASD and the possibility of children with this disorder to be high functioning in early years. Additionally, it is possible the proportions of neighbourhoods with different levels of clustering of kindergarten children with ASD observed across provinces and territories are not large enough to observe the association between clustering and kindergarten children's developmental health.

When examining specific areas of development, kindergarten children with ASD scored significantly higher in the Language and Cognitive Development domain compared to kindergarten children with developmental disabilities other than ASD (Janus et al., 2018b). While there has been no systematic mapping of ASD services' availability and usage among children with ASD across provinces and territories in Canada, a literature review on service use among children with ASD aged 3 to 9 years found that speech-language therapy is often the most common treatment they receive (Irvin, Patten, & Boyd, 2014). In contrast, our results show there is no specific area of development where the lowest or highest average proportion of kindergarten children demonstrated vulnerability in all provinces and territories, across all neighbourhoods with different levels of spatial clusters of kindergarten children with ASD. There were also no neighbourhoods with a specific level of spatial cluster of kindergarten children with ASD where kindergarten children consistently demonstrated the lowest or highest average proportion of vulnerability across all areas of development within a province or territory.

Since in our analyses we were able to differentiate between neighbourhoods with higher (six or more) and lower frequencies of kindergarten children with ASD, we demonstrated that there was no consistency in developmental vulnerabilities among those neighbourhoods. This emphasizes the importance of recognizing that early intervention service planning cannot be determined based on the size of the spatial clusters of children with ASD in a neighbourhood, but rather the developmental vulnerabilities observed in the neighbourhoods of their residence.

There are several strengths of this study. Until now, there was no population-based database with which the objectives of this study could be investigated. The use of the large EDI database presents an unprecedented opportunity to examine the prevalence of kindergarten children with ASD, as well as the developmental vulnerability of children living in neighbourhoods with no kindergarten children with ASD and different levels of spatial clusters of kindergarten children with this disorder across provinces and territories in Canada. Such analysis is not possible through sample-based research where children with ASD are commonly not available or included in sufficient numbers. The nation-wide implementation of the EDI provides a large representative sample, improving generalizability of study findings.

There are also several limitations of this study. Implementation of the EDI did not occur every year from 2010 to 2015 in every province and territory, with more implementations occurring in some provinces and territories compared to others, which could have influenced the estimates of numbers of kindergarten children with ASD at the neighbourhood level. No formal evaluation yet has been conducted to compare the

diagnosis reported on the EDI to data from health services based on ‘gold standard’ diagnostic procedures for ASD. However, the robustness of the EDI data as a source of ASD diagnosis can be ascertained through several points. First, findings from Manitoba and Ontario show there is fair concordance between EDI and population-level administrative data when identifying children with ASD (Kappa = 0.329;  $p < 0.001$ ) (Reid-Westoby et al., 2018). Second, teachers are provided with extensive training materials to complete the EDI, which include an EDI Guide, electronic EDI Teacher’s Manual, EDI Training Video, as well as a variety of presentations (<https://edi.offordcentre.com/teachers/>). While in the past few years, most training has moved to the online delivery, data included in this study were collected when most provinces conducted in-person training for teachers. Third, teachers report medical diagnoses on the EDI based on identification by accredited external health professionals (doctor or psychological professional), as per information shared by parents with the school. Fourth, social bias in case detection may not be a limitation of educational sources such as the EDI. Nonetheless, it is possible that ASD diagnosis is subject to over- or under-reporting, which may differ by place of residence across the country. Fourth, no information of participation in any early intervention is available for this sample. Finally, while lack of inclusion of sociodemographic variables in this report may be considered as limitation, this decision was dictated by the lack of evidence of a consistent association between diagnosis of ASD and socioeconomic status reported earlier.

## **6. Conclusions**

As a large population-level database, the EDI demonstrates significant utility from a population health perspective. Knowledge of prevalence of children with kindergarten teacher- reported ASD, as well as developmental vulnerability of kindergarten children living in neighbourhoods with and without kindergarten children with ASD at school entry derived from the EDI database presents a pragmatic first step to determine the association of type and location of services with their developmental health, which is not only crucial for early intervention service planning, but also for facilitating the planning of services for later years as children with ASD grow older.



Table 1

*Implementation of EDI across provinces and territories in Canada from 2010 to 2015*

	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	North west Territories	Newfoundland and Labrador	Nova Scotia	Yukon	New Brunswick	Prince Edward Island	Quebec	Nunavut
2010	32184	0	17413	24671	8167	0	0	756	340	0	0	0	0
2011	37494	11841	17955	21767	5151	0	1088	2317	341	0	0	0	0
2012	55257	0	12710	12406	539	585	2090	2198	365	0	0	65042	0
2013	0	12886	16541	29854	7955	623	4835	8398	399	0	0	0	0
2014	0	0	0	1277	0	613	5069	1376	0	0	0	0	0
2015	132873	13224	0	0	0	602	0	8513	0	0	0	0	0

Table 2

*Number of kindergarten children with ASD at the neighbourhood level*

	Canada	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	North west Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
Number of neighbourhoods	n=1985	n=790	n=74	n=265	n=297	n=55	n=3	n=41	n=57	n=6	n=396
Number of kindergarten children with ASD per neighbourhood	Min 0 Max 21 Mean 2.89 (SD) (3.02)	0 21 3.82 (3.24)	0 12 4.04 (3.65)	0 13 1.76 (2.08)	0 15 2.84 (2.52)	0 8 1.51 (1.90)	3 4 3.33 (0.58)	0 18 5.15 (4.71)	0 15 4.72 (3.71)	0 5 2.00 (1.67)	0 12 1.26 (1.63)

Table 3

*Distribution of neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec	
	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
0	80	10.1	12	16.2	86	32.5	45	15.2	22	40.0			8	19.5	7	12.3	1	16.7	158	39.9
1	118	14.9	13	17.6	63	23.8	63	21.2	14	25.5			1	2.4	5	8.8	1	16.7	116	29.3
2	129	16.3	7	9.5	50	18.9	50	16.8	7	12.7			4	9.8	6	10.5	3	50.0	66	16.7
3	123	15.6	8	10.8	32	12.1	47	15.8	4	7.3	2	66.7	6	14.6	9	15.8			24	6.1
4	74	9.4	8	10.8	7	2.6	32	10.8	2	3.6	1	33.3	3	7.3	6	10.5			12	3.0
5	77	9.7	6	8.1	10	3.8	19	6.4	3	5.5			4	9.8	1	1.8	1	16.7	7	1.8
6 or more	189	23.9	20	27.0	17	6.4	41	13.8	3	5.5			15	36.6	23	40.4			13	3.3

Table 4

*Developmental vulnerability at the neighbourhood level of kindergarten children in neighbourhoods with no kindergarten children with ASD*

	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
% overall vulnerability per neighbourhood	25 (8.7)	24.9 (15.3)	31.3 (10.1)	35.8 (10.2)	29.7 (10.1)	22.4 (11.7)	29.3 (7.8)	40.9 (0.0)	24.5 (7.3)
% vulnerability on Physical Health and Well-Being domain per neighbourhood	10.9 (5.3)	8.7 (7.9)	15 (7.2)	18.7 (8.8)	14.1 (5.7)	5.4 (4.2)	13.4 (4.9)	28.2 (0.0)	7.2 (4.3)
% vulnerability on Social Competence domain per neighbourhood	10.9 (5.2)	8.3 (6.1)	11.1 (5.1)	13.5 (5.0)	12.1 (8.7)	9 (5.1)	12.4 (4.1)	14.1 (0.0)	7.8 (4.1)
% vulnerability on Emotional Maturity domain per neighbourhood	11.9 (4.8)	10.5 (7.0)	12.2 (5.2)	16.7 (6.2)	13.2 (8.1)	10.5 (8.3)	14 (5.9)	20.3 (0.0)	13.9 (5.5)
% vulnerability on Language and Cognitive Development domain per neighbourhood	6.3 (3.7)	8.4 (6.0)	11.7 (5.9)	9.8 (4.8)	12.8 (6.2)	10.9 (5.4)	8.2 (3.2)	9.5 (0.0)	9.4 (4.5)
% vulnerability on Communication Skills and General	11 (5.2)	13.7 (11.5)	16 (7.0)	17.6 (7.9)	14.6 (6.1)	10.1 (5.9)	11.7 (3.2)	17.5 (0.0)	8.4 (4.1)

Knowledge  
domain per  
neighbourhood

\*There were no neighbourhoods with no kindergarten children with ASD in Northwest Territories

Table 5

*Overall vulnerability at the neighbourhood level of kindergarten children living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1	27.1 (6.8)	24.8 (11.7)	32.5 (9.6)	32.2 (10.5)	34.1 (10.6)		19.2 (0.0)	33.8 (10.3)	47.1 (0.0)	24.6 (7.6)
2	26.9 (7.5)	37.1 (8.8)	31.1 (9.3)	33.6 (8.5)	30.6 (8.4)		21.4 (3.8)	31.6 (6.2)	36.2 (6.6)	25.2 (7.1)
3	27.1 (5.8)	28.1 (8.8)	31.0 (8.0)	33.7 (7.4)	25.9 (3.1)	46.3 (1.5)	26.1 (13.5)	25.2 (7.8)		24.2 (4.3)
4	28.1 (6.9)	38.8 (9.6)	30.5 (9.9)	35.3 (9.2)	36.1 (7.3)	32.1 (0.0)	20.9 (5.0)	31.2 (6.4)		27.2 (6.1)
5	28.2 (6.4)	31.8 (6.1)	29.9 (9.9)	34.3 (7.6)	29.0 (10)		15.3 (5.7)	38.2 (0.0)	45.7 (0.0)	22.9 (5.6)
6 or more	28.6 (7.0)	33.0 (10.3)	29.4 (7.0)	36.0 (7.8)	30.8 (5.0)		20.6 (5.2)	31.1 (3.1)		26.3 (5.2)

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Appendices

Appendix A

*Demographic characteristics of neighbourhoods with no kindergarten children with ASD and with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Characteristics of the average neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	North west Territories	Newfound land and Labrador	Nova Scotia	Yukon	Quebec
0	Mean age	5.7	5.7	5.7	5.6	5.7		5.7	5.7	5.8	6.0
	(SD)	(0.1)	(0.1)	(0.1)	(0.0)	(0.0)		(0.1)	(0.1)	(0.0)	(0.0)
	Mean % male	50.8	60.0	51.9	51.4	50.7		48.9	60.0	55.0	50.4
	(SD)	(7.5)	(18.8)	(4.0)	(4.3)	(4.3)		(6.1)	(30.3)	(0.0)	(5.5)
1	Mean % EFSL	8.7	30.8	16	10.1 (15.1)	4.3		0.4	3.8	9.4	12.6
	(SD)	(10.7)	(35.5)	(16.5)		(2.5)		(0.7)	(5.1)	(0.0)	(14.5)
	Mean age	5.7	5.7	5.7	5.7	5.7		5.7	5.7	5.7	6.0
	(SD)	(0.0)	(0.1)	(0.1)	(0.0)	(0.0)		(0.0)	(0.0)	(0.0)	(0.0)
2	Mean % male	51.3	48.2	51.9	50.1	52.3		54.1	48.5	57.3	51.1
	(SD)	(3.9)	(15.0)	(3.9)	(4.4)	(4.1)		(6.0)	(3.0)	(0.0)	(5.4)
	Mean % EFSL	9.0	9.2	16.4	11.5 (15.4)	5.3		2.2	20.2	1.8	12.2
	(SD)	(9.7)	(9.0)	(15.7)		(4.2)		(3.1)	(21.6)	(0.0)	(12.1)
3	Mean age	5.7	5.7	5.7	5.7	5.7		5.6	5.7	5.72	6.0
	(SD)	(0.0)	(0.0)	(0.1)	(0.0)	(0.0)		(0.1)	(0.0)	(0.0)	(0.0)
	Mean % male	51.3	49.5	50.9	50.9	53.0		51.6	50.7	50.8	51.9
	(SD)	(2.9)	(2.1)	(4.0)	(3.6)	(1.9)		(3.9)	(3.3)	(6.1)	(4.7)
3	Mean % EFSL	9.1	12.2	16.3	12.0 (17.8)	5.1		5.7	8.3	10.1	14.7
	(SD)	(8.6)	(9.1)	(16.3)		(7.0)		(11)	(5.0)	(3.3)	(16.0)
	Mean age	5.7	5.7	5.6	5.6	5.7	5.7	5.6	5.7		6.0
	(SD)	(0.0)	(0.0)	(0.1)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)		(0.0)
3	Mean % male	50.9	49.0	51.6	51.7	51.5	51.3	47.3	52.0		51.5
	(SD)	(3.4)	(1.4)	(4.7)	(2.5)	(1.6)	(0.1)	(4.1)	(3.6)		(3.7)
	Mean % EFSL	11.9	8.6	17.1	17.2 (20.0)	2.7	2.8	1.9	7.5		20.5
	(SD)	(10.6)	(6.0)	(14.1)		(1.5)	(2.7)	(3.1)	(4.4)		(20.8)

4	Mean age	5.7	5.7	5.7	5.7	5.7	5.7	5.7	5.7	5.7	6.0
	(SD)	(0.0)	(0.0)	(0.1)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)	(0.0)
	Mean % male	51.1	51.4	50.6	51.7	53.5	50.9	52.1	52.4	52.4	49.9
	(SD)	(3.0)	(1.7)	(4.6)	(2.3)	(0.4)	(0.0)	(4.2)	(2.6)	(2.6)	(3.6)
5	Mean % EFSL	14.1	16.0	7.2	19.5 (22.4)	5.2	9.0	1.4	6.7	6.7	17.5
	(SD)	(12.7)	(9.3)	(7.4)		(0.1)	(0.0)	(1.8)	(5.4)	(5.4)	(21.4)
	Mean age	5.7	5.7	5.7	5.6	5.7		5.7	5.7	5.71	6.0
	(SD)	(0.0)	(0.0)	(0.1)	(0.0)	(0.0)		(0.0)	(0.0)	(0.0)	(0.0)
6 or more	Mean % male	51.0	50.9	50.2	50.6	50.4		51.8	53.3	51.1	49.8
	(SD)	(2.8)	(3.0)	(2.9)	(2.3)	(1.2)		(3.1)	(0.0)	(0.0)	(2.2)
	Mean % EFSL	11.5	15.2	12.2	18.8 (20.2)	10.6		1.8	0.8	2.6	31.7
	(SD)	(8.8)	(6.6)	(9.7)		(1.1)		(1.1)	(0.0)	(0.0)	(21.5)
6 or more	Mean age	5.7	5.7	5.7	5.6	5.7		5.6	5.7		6.0
	(SD)	(0.0)	(0.0)	(0.1)	(0.0)	(0.0)		(0.1)	(0.0)		(0.0)
	Mean % male	51.5	51.0	52.2	51.4	50.4		51.6	52.2		52.6
	(SD)	(2.4)	(1.6)	(1.7)	(2.3)	(2.1)		(2.0)	(2.9)		(3.3)
6 or more	Mean % EFSL	12.9	11.3	13.7	24.5 (24.8)	12.8		1.8	3.3		30.7
	(SD)	(10.0)	(6.1)	(9.4)		(1.8)		(2.3)	(2.2)		(21.4)

## Appendix B

*Vulnerability on Physical Health and Well-Being Domain at the neighbourhood level of kindergarten children living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1	11.9 (5.0)	10.4 (7.0)	15.7 (6.7)	16.6 (7.7)	18.0 (7.0)		5.1 (0.0)	17.4 (11.0)	29.6 (0.0)	7.6 (4.2)
2	11.7 (5.1)	15.6 (5.5)	13.9 (5.8)	17.3 (6.7)	14.4 (7.4)		9.6 (2.4)	16.6 (5.2)	21.3 (3.2)	7.4 (3.8)
3	11.4 (4.6)	12.1 (6.0)	14.0 (5.7)	16.7 (5.5)	11.9 (1.3)	27.2 (2.3)	10.5 (8.1)	12.0 (4.5)		6.7 (2.6)

4	11.9 (4.5)	17.6 (8.2)	16.9 (6.7)	18.6 (6.0)	19.1 (7.0)	17.8 (0.0)	6.5 (3.0)	14.9 (3.6)		8.6 (4.3)
5	12.0 (5.4)	13.6 (4.9)	14.8 (6.7)	17.8 (6.1)	13.8 (7.3)		5.4 (2.3)	20.5 (0.0)	27.8 (0.0)	6.9 (2.3)
6 or more	12.0 (5.0)	14.8 (5.6)	14.2 (6.1)	17.4 (5.3)	15.1 (4.9)		7.4 (2.9)	15.8 (3.2)		7.9 (3.4)

### Appendix C

*Vulnerability on Social Competence Domain at the neighbourhood level of kindergarten children living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1	11.3 (3.9)	7.8 (4.4)	11.9 (4.8)	11.7 (5.7)	13.1 (5.4)		8.0 (0.0)	16.0 (9.1)	15.3 (0.0)	8.2 (4.3)
2	11.1 (4.5)	14.7 (10.1)	11.4 (5.0)	13.0 (4.8)	9.9 (3.6)		10.1 (2.7)	13.0 (4.1)	12.9 (2.6)	8.4 (4.0)
3	11.3 (3.6)	10.7 (3.0)	12.1 (5.1)	12.9 (4.0)	8.2 (1.3)	19.4 (3.1)	13.7 (9.7)	10.1 (2.7)		8.3 (3.0)
4	12.0 (4.1)	13.4 (4.7)	12.5 (7.5)	13.8 (5.2)	12.5 (2.6)	11.3 (0.0)	8.0 (3.4)	14.2 (5.6)		8.5 (2.6)
5	12.1 (3.8)	10.4 (3.8)	11.9 (6.5)	14.3 (4.3)	9.4 (3.8)		6.2 (1.4)	15.1 (0.0)	21.1 (0.0)	7.7 (2.3)
6 or more	12.3 (3.9)	12.8 (5.8)	10.6 (3.6)	14.8 (4.6)	8.9 (1.1)		8.9 (4.0)	13.7 (2.2)		8.6 (3.4)

Appendix D

*Vulnerability on Emotional Maturity Domain at the neighbourhood level of kindergarten children living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1	13.1 (4.4)	10.8 (6.0)	13.4 (5.2)	14.4 (6.4)	14.0 (4.9)		6.1 (0.0)	14.9 (7.1)	23.5 (0.0)	13.8 (4.8)
2	12.9 (4.7)	17.4 (6.4)	12.5 (5.1)	16.0 (4.8)	11.1 (3.5)		8.1 (1.5)	14.5 (4.3)	17.8 (2.2)	13.7 (5.1)
3	12.7 (3.2)	11.5 (5.3)	12.0 (4.7)	15.9 (4.2)	10.2 (0.2)	24.3 (4.7)	14.2 (7.1)	11.4 (3.9)		13.5 (3.0)
4	13.0 (3.8)	15.9 (3.0)	11.5 (3.6)	16.3 (5.0)	13.9 (1.2)	12.7 (0.0)	7.9 (0.8)	15.4 (5.2)		15.0 (4.0)
5	13.7 (4.3)	13.3 (4.1)	12.1 (5.3)	14.9 (3.0)	12.1 (3.8)		7.1 (1.7)	17.0 (0.0)	23.0 (0.0)	11.4 (2.8)
6 or more	13.8 (4.1)	14.8 (6.7)	12.2 (4.0)	17.3 (4.4)	11.9 (0.5)		9.9 (3.3)	14.9 (2.6)		13.5 (3.1)

Appendix E

*Vulnerability on Language and Cognitive Development Domain at the neighbourhood level of kindergarten children living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1	7.0 (3.1)	8.0 (5.9)	11.6 (4.8)	8.9 (4.8)	16.1 (6.7)		11.6 (0.0)	8.6 (6.4)	10.6 (0.0)	9.5 (4.5)
2	6.6 (3.6)	15.8 (8.1)	10.5 (4.8)	9.8 (4.7)	14.4 (5.1)		8.1 (3.0)	7.9 (4.6)	7.5 (3.1)	10.2 (4.5)
3	7.1 (3.0)	13.3 (6.7)	10.9 (4.6)	9.6 (4.0)	10.6 (2.1)	22.8 (2.5)	10.9 (8.7)	7.0 (2.8)		9.8 (3.6)
4	7.6 (3.3)	16.9 (7.4)	10.8 (4.3)	10.0 (4.0)	15.7 (6.4)	13.2 (0.0)	6.6 (3.2)	8.7 (2.5)		10.9 (3.4)
5	7.2 (2.9)	12.6 (3.1)	10.5 (8.4)	9.8 (3.8)	9.0 (5.3)		6.0 (2.8)	6.6 (0.0)	15.3 (0.0)	7.8 (2.6)
6 or more	7.3 (3.3)	13.0 (7.0)	9.3 (3.4)	9.6 (3.4)	10.3 (2.8)		7.2 (2.8)	8.0 (2.2)		9.7 (2.9)

Appendix F

*Vulnerability on Communication Skills and General Knowledge Domain at the neighbourhood level of kindergarten children living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
1	12.1 (4.3)	12.0 (5.2)	16.6 (7.2)	15.1 (7.6)	16.3 (5.5)		10.2 (0.0)	15.7 (8.1)	20.0 (0.0)	8.8 (4.1)
2	11.9 (4.7)	18.6 (4.5)	16.5 (6.6)	15.8 (6.3)	14.2 (4.6)		9.3 (1.4)	12.6 (3.6)	14.4 (7.2)	8.7 (4.0)
3	12.7 (4.2)	13.9 (5.3)	16.1 (6.6)	16.1 (6.0)	13.1 (2.2)	24 (2.0)	10.9 (6.8)	12.2 (4.7)		9.4 (3.8)
4	13.5 (5.0)	20.6 (4.5)	12.7 (4.5)	17.2 (6.7)	18.8 (2.0)	16.4 (0.0)	9.7 (5.8)	14.8 (3.1)		10.1 (4.8)
5	12.6 (3.2)	16.8 (3.5)	15.2 (8.5)	17.0 (6.4)	13.7 (5.7)		7.2 (2.8)	18.1 (0.0)	25.0 (0.0)	9.5 (3.7)
6 or more	13.8 (4.6)	17.2 (6.3)	14.5 (4.3)	18.1 (6.2)	15.5 (2.3)		9.5 (2.9)	13.8 (2.7)		10.9 (4.0)

Appendix G

*Sample questions from the Early Development Instrument*

Section A – Physical Well-Being				
Since the start of school in the fall, has this child sometimes (more than once) arrived:	Yes	No	Don't know	
2. over- or underdressed for school-related activities				
3. too tired/sick to do school work				
4. late				
Section B - Language and Cognitive Skills				
How would you rate this child's:	Very good/good	Average	Poor/very poor	Don't know
1. ability to use language effectively in English				
2. ability to listen in English				
3. ability to tell a story				
4. ability to take part in imaginative play				
Section C - Social and Emotional Development				
Would you say that this child:	Often or very true	Sometimes or somewhat true	Never or not true	Don't know
3. plays and works cooperatively with other children at the level appropriate for his/her age				
4. is able to play with various children				
5. follows rules and instructions				



\*Entire EDI questionnaire can be found here: <https://edi-offordcentre.s3.amazonaws.com/uploads/2019/01/EDI-ON-ENG-2018.pdf>

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**Chapter Three: Association between neighbourhood socioeconomic status and developmental vulnerability of kindergarten children with Autism Spectrum Disorder: A population level study**

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### **Abstract**

There is limited knowledge about the relationship between neighbourhood socioeconomic status (SES) and development of kindergarten children with ASD. The objectives of this study are to determine, among kindergarten children with ASD (1) the developmental vulnerability in neighbourhoods with different levels of spatial clusters of children with ASD; (2) the association between neighbourhood SES and developmental vulnerability at the individual level, while controlling for family SES and neighbourhood clustering; (3) the association between neighbourhood SES and developmental vulnerability at the individual level, while controlling for family SES; and (4) the association between neighbourhood SES and developmental vulnerability at the neighbourhood level, while controlling for family SES and spatial cluster level of children with ASD in neighbourhoods across provinces and territories in Canada. This study used data from a population level database of child development in kindergarten, collected with the Early Development Instrument (EDI). Data from 10 provinces and territories were used. Neighbourhood SES was assessed with an SES index created using 10 variables from the 2011 Canadian Census and 2010 Taxfiler data. Family SES was assessed using 4 variables from the 2016 Canadian Census. Descriptive statistics and regression-based models were used in this study. In Ontario, British Columbia, Manitoba, and Newfoundland and Labrador, higher neighbourhood SES was associated with lower likelihood of developmental vulnerability. This finding emphasizes the importance of addressing neighbourhood deprivation to support the development of children with ASD.

Key words: ASD, kindergarten, developmental disabilities, behaviour, Early Development Instrument, neighbourhood

## **1. Introduction**

Autism Spectrum Disorder (ASD) is a commonly diagnosed neurodevelopmental disorder in Canada, with a national prevalence estimate of 1 per 66 children diagnosed in 2015 (Public Health Agency of Canada, 2018). ASD is a heterogeneous neurodevelopmental disorder with no unifying pathological or neurobiological etiology (Geschwind & Levitt, 2007). According to the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM – 5, American Psychiatric Association, 2013), the core dysfunctions of ASD occur in two behavioural domains: difficulties in social communication and social interaction, as well as restricted, repetitive behaviours and interests (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). Children with ASD have heterogeneous developmental trajectories (Fountain, Winter, & Bearman, 2012). There is a growing body of literature examining the risk factors for the occurrence of ASD, which include a variety of genetic, environmental, and epigenetic factors (Chaste & Leboyer, 2012; Grabrucker, 2012; Karimi, Kamali, Mousavi, & Karahmadi, 2017). There is also emerging evidence regarding factors influencing language development of children with ASD – for example, it has been found that children with ASD who are raised by parents with a high level of education demonstrate earlier language development (Fusaroli, Weed, Fein, & Naigles, 2018; Grandgeorge et al., 2009).

Substantial evidence indicates that higher socioeconomic status (SES) is associated with better health (Fiscella & Williams, 2004). Differences in health across levels of SES are referred to as the socioeconomic gradient, highlighting that differences in health outcomes are gradual and occur across the full spectrum of the SES continuum

(Syme & Berkman, 1976; Fiscella & Williams, 2004). Lower SES is associated with higher morbidity, mortality, and disability rates for almost every disease and illness (Syme & Berkman, 1976; Roberts & Power, 1996). On the other hand, higher SES is associated with significant benefits to health (Schreier & Chen, 2013), although the positive relationship between SES and health can plateau at increasingly higher levels of SES (Carpiano, Lloyd, & Hertzman, 2009).

There is increasing consensus that inequalities in health outcomes of a population are usually not fully accounted for by combinations of individual level factors and may therefore be attributable to factors that operate at an aggregate level, such as neighbourhood characteristics (Pickett & Pearl, 2001). Pickett & Pearl proposed that contextual factors, such as characteristics of neighbourhoods, may be the most important determinants of health of a population – highlighting the importance of examining the impact of neighbourhood SES on children’s health outcomes at the population level. Neighbourhood deprivation is a feature of the neighbourhood environment, which is commonly defined by the proportion of residents with low SES, unemployed people and/or people receiving welfare assistance (Li, Sjostedt, Sundquist, Zoller, & Sundquist, 2014). Household income is typically geographically clustered, resulting in neighbourhoods with different levels of socioeconomic deprivation (Emerson, 2012). There is growing evidence demonstrating that a significant relationship exists between neighbourhood deprivation and children’s developmental health, especially cognitive development (McCulloch, 2006; Sellstrom & Bremberg, 2006). Living in low-income neighbourhoods negatively impacts children’s school readiness, academic achievement,

and externalizing behaviour problems, even after controlling for individual level factors (McCulloch, 2006).

The relationship between neighbourhood SES and health of children with ASD remains largely unexamined. Thus far, research addressing the association between individual and neighbourhood SES with prevalence of children with ASD shows mixed findings (Li et al., 2014; Emerson, 2012; Delobel-Ayoub et al., 2015; Bhasin & Schendel, 2007; Thomas et al., 2012; Hock & Ahmedani, 2012). There is some evidence indicating that spatial clustering of children with ASD is associated with neighbourhood resources that can facilitate diagnosis – including number of pediatricians, number of advocacy organizations, and regional center spending on ASD services (Mazumdar, Winter, Liu, & Bearman, 2013). Children who live in close proximity of other children previously diagnosed with ASD are more likely to be diagnosed with ASD as well – which has been attributed to the diffusion of information about ASD through social networks, a phenomenon that can lead to spatial clustering of children with ASD in neighbourhoods (Liu, King, & Bearman, 2010). In this context, it can be hypothesized that children with ASD who live in spatial clusters of children with this disorder in neighbourhoods may also have better developmental health as a result of information sharing about ASD early intervention services through social networks. Thus, the larger the spatial cluster of children with ASD, the better their developmental health is expected to be.

There is strong impetus to further explore the relationship between individual and neighbourhood SES with development of children with ASD. Reliable information on this relationship across provinces and territories is needed to identify regions with ASD

populations showing poor development with inadequate access to necessary intervention programs or services. Providing support according to the needs of different areas can have long-term benefits on young children, as intensive behavioural interventions provided to preschool and school aged children with ASD have demonstrated long-term improvements in intellectual, academic, communication, social, and daily living skills (Eikeseth, Smith, Jahr, & Eldevik, 2007; Jacobson, Mulick, & Green, 1998). The median age of ASD diagnosis remains over age of 4 years, therefore identifying the socioeconomic gradient in the development of kindergarten children with ASD between the ages of 4 to 6 years presents an optimal opportunity to target early interventions (Janus et al., 2018; Monteiro et al., 2015).

The relationships between neighbourhood characteristics and child health outcomes have been largely a subject of studies which examined health outcomes at the individual level, or of ecological studies, where health outcomes are examined at the group level (Sellstrom & Bremberg, 2006). However, these studies do not consider the nested structure of the data, where families and children living in a neighbourhood are more likely to be similar to one another than those living in a different neighbourhood. The research objectives of this study were designed to address such shortcomings in the population of kindergarten children with ASD. There is particular value in examining the relationship between neighbourhood SES and health of children with ASD using a multilevel approach, where their health outcomes are examined at the individual level while accounting for clustering of these children in neighbourhoods. Our Objective 1 is to determine the developmental vulnerability in neighbourhoods with different levels of



spatial clusters of children with ASD. If any level of variability in health outcomes of children is explained by differences between neighbourhoods, it is not appropriate to examine the relationship between neighbourhood SES and health outcomes of children without considering the clustering of this population in neighbourhoods. Objective 2 is to determine the association between neighbourhood SES and developmental vulnerability at the individual level, while controlling for family SES and neighbourhood clustering. If no variability in health outcomes of children is explained by differences between neighbourhoods, individual-based analysis to examine the relationship between neighbourhood SES and health outcomes of children is warranted. Objective 3, therefore, is to determine the association between neighbourhood SES and developmental vulnerability at the individual level, while controlling for family SES. An ecological analysis approach is valuable for illustrating whether the relationship between neighbourhood SES and health of children with ASD differs according to the unit of analysis, which has important implications for service planning. In Objective 4, we determine the association between neighbourhood SES and developmental vulnerability at the neighbourhood level, while controlling for family SES and spatial cluster level of children with ASD in neighbourhoods across provinces and territories in Canada.

## **2. Methods**

### ***2.1 Study design***

A population level cross-sectional study design was used to address the research objectives.

## ***2.2 Kindergarten in Canada***

In Canada, children start kindergarten at the age of 4 to 5 years depending on the province or territory. In Ontario, children can begin school in September of the calendar year they turn 4 years old, called “Junior Kindergarten”. However, the majority of children in Canada begin school in the fall of the year they turn five, called “Senior Kindergarten”. In the present study, only data collected at the Senior Kindergarten level are used.

## ***2.3 Data Sources***

### ***2.3.1 Early Development Instrument database***

To determine the developmental vulnerability of kindergarten children with ASD, this study used data from the large, population-wide database of child development in kindergarten, collected using the Early Development Instrument (EDI). The EDI is currently widely used across Canada, similar to a census (Janus & Offord, 2007). It has been administered at the population level in most Canadian provinces and territories since 2004 (Janus & Offord, 2007).

The EDI is a measure of developmental health (i.e., development in behavioural, physical, and cognitive areas, Keating & Hertzman, 1999), which is completed by teachers for children aged 4-6 years in their second term of senior kindergarten (Janus & Offord, 2007). It contains 103 items covering five broad domains of developmental health: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge (Janus &

Offord, 2007). The EDI also includes a number of demographic questions, including child's date of birth, sex, first language, and "English or French as a Second Language Status" (E/FSL), which indicates a child's lack of fluency in the school's language of instruction, and postal code of child's residence. The psychometric properties and validity of the EDI have been reported in many studies, based on its differential item functioning, multilevel validity, factor structure, internal consistencies, as well as associations with other developmental outcomes (Janus & Offord, 2007; Janus et al., 2007; Guhn et al., 2016).

Within each EDI domain, there are a series of questions, some of which are dichotomous (e.g., 0=no, 10=yes – unless otherwise stated), while others use a Likert scale (e.g., Never/not true=0, Sometimes/somewhat true=5, Often/very true=10) (Janus & Offord, 2007). To determine the overall score for a domain, the responses to questions are summed and divided by the number of questions. The scores are not interpreted in a clinical/diagnostic manner for individual children; rather, they are always compared at a group level (e.g., between boys and girls, children in geographic communities etc.), where the mean and standard deviation of scores are considered and effect sizes of differences reported. The score is referenced to a normative baseline, where scores below the 10<sup>th</sup> percent cut-off indicate vulnerability on a domain, and vulnerability on one or more domains indicates overall vulnerability (Janus & Duku, 2007).

The EDI also includes teacher report on any health diagnosis the child may have, if they are aware "based on parent or health provider report". These items have been

included on the EDI since the 2009/10 school year and include a list of over 30 most frequent childhood diagnoses (Janus et al., 2018). ASD is one of these diagnoses.

### ***2.3.2 Census Canada and Income Taxfiler databases***

To determine neighbourhood SES, socioeconomic and demographic information was derived from the 2006 and 2011 Canadian Census and the matching 2005 and 2010 Income Taxfiler databases (since Census data report on the previous year) at the smallest geographic areas available, which were Dissemination Blocks (DBs), then aggregated at the neighbourhood level based on a custom neighbourhood boundary definition (Forer et al. 2019; Guhn et al., 2016). After the EDI variables had been merged with the 2006 and 2011 Census and 2005 and 2010 Income Taxfiler demographic and SES variables at the neighbourhood level, a small subset of 10 variables was identified to create a neighbourhood SES index. This index represents an optimal compromise between maximizing the variance explained in the developmental health outcomes measured using the EDI, as well as restriction in the number of variables to a reasonable number for interpretation and intervention (Table 1) (Forer et al., 2019; Webb et al., 2017).

Individual child's family SES (henceforth, "family SES") was determined by a proxy measure consisting of 4 variables derived from the 2016 Census, including marital status, education, language/immigration, and residential stability. For consistency with the neighbourhood SES index, these 4 variables were similar to 4 of the variables included in the neighborhood index (Table 1). Family SES was determined at the Dissemination Area (DA; a small area composed of one or more neighbouring DBs and

consists of approximately 400 to 700 persons) associated with a child's postal code, which meant that all children living in this same small geographic unit were assigned the same family SES. The DA level SES was considered to be an appropriate proxy for family SES as it is a small geographic unit, therefore the SES of those living in the same unit were expected to be similar. This is a standard practice for analyses of large secondary databases, where individual family variables are not available (Carpiano et al., 2009).

## ***2.4 Data Linkage***

### ***2.4.1 Defining geographic neighbourhood boundaries***

A detailed set of criteria was used to create discrete neighbourhoods to analyze the EDI data (Guhn et al., 2016). Neighbourhood boundaries were established to reflect geographic and socioeconomic diversity across neighbourhoods (Guhn et al., 2016). Overall, there were 2,038 neighbourhoods with total population sizes of 355 to 95,295 people based on the 2006 Census (Webb et al., 2017). In each neighbourhood, there was a minimum of 50 and no more than 400-600 EDI records per unit (Guhn et al., 2016).

### ***2.4.2 Linking Census Canada, Income Taxfiler, EDI data***

When the individual EDI variables were merged with the 4 SES variables from the 2016 Census using postal codes, 910 kindergarten children with ASD, representing 15.7% of the kindergarten children with ASD with available EDI records were excluded (Figure 1). This exclusion was due to the lack of one-to-one match between postal codes of residence of kindergarten children with ASD from the EDI records with the postal

codes included in the 2016 Postal Code Conversion File (PCCF; Statistics Canada, 2018), which provides correspondence between postal codes and standard geographic areas for which Census data are produced. This lack of one-to-one match led to the exclusion of 29 postal codes, representing 0.6% of the available postal codes for the kindergarten children with ASD included in the EDI records.

### ***2.5 Sample***

This study used linked EDI-SES data collected for the school years 2009/10 to 2014/15. There were between 1 and 6 implementations of the EDI per jurisdiction (province/territory) in those six years (Appendix 1). New Brunswick, Prince Edward Island, and Nunavut were excluded from the study sample, as EDI data were not collected in these provinces during the study period. There were 5804 children with ASD, representing 1% of the kindergarten children with available EDI records. The numbers of kindergarten children with ASD with individual level SES information available for analysis are summarized in Appendix 2.

### ***2.6 Analyses***

To examine spatial clusters, neighbourhoods were categorized according to the number of kindergarten children with ASD, ranging from neighbourhoods with one child to those with two, three, four, five, and six or more. Neighbourhoods were stratified in this manner to examine developmental vulnerability of kindergarten children with ASD living in neighbourhoods with incremental increase in the number of children with ASD in a neighbourhood. Descriptive statistics were used to examine average proportions of

kindergarten children with ASD demonstrating developmental vulnerability while living in neighbourhoods with different levels of spatial clusters. Tests for linearity were conducted to determine whether the relationships between increasing sizes of spatial clusters of children with ASD in a neighbourhood and developmental vulnerability were linear or not.

Multilevel binary logistic regression analyses were used to examine the association between neighbourhood SES and child developmental vulnerability at the individual level (yes/no), while controlling for family SES, demographic characteristics, and neighbourhood clustering. Since a minimum of 40 level 2 units are needed for multilevel logistic modeling, provinces and territories with less than 40 neighbourhoods were excluded from the multilevel analyses and included in the logistic regression analyses described below (Schoeneberger, 2016). Also, if the proportion of variability explained in the chance of a kindergarten child with ASD demonstrating developmental vulnerability across neighbourhoods was greater than zero in provinces with at least 40 neighbourhoods, this was interpreted as a necessity to account for neighbourhood level variation and multilevel models were created. If no variability explained in the chance of a kindergarten child with ASD demonstrating developmental vulnerability was attributed to between neighbourhood differences in these provinces, single level binary logistic regression analyses were conducted as described below.

Pan-Canadian and province specific approaches were used to conduct the multilevel analyses. In the first pan-Canadian approach (pan-Canadian analysis # 1), six provinces with at least 40 neighbourhoods were included in the analysis, which were

Ontario, Manitoba, Alberta, British Columbia, Nova Scotia, and Quebec. In the second pan-Canadian approach (pan-Canadian analysis # 2), Ontario, British Columbia and Quebec were included as separate units, and remaining provinces were grouped into Prairies (Alberta, Saskatchewan, and Manitoba), and Atlantic provinces (Nova Scotia, Newfoundland), following the methodology established by Webb et al. (2020). The Prairies and Atlantic provincial groups were created to ensure inclusion of regions that had fewer than 40 neighbourhoods per province.

The multilevel models were analyzed using MLwiN and used in a sequential manner for both the pan-Canadian and province specific analyses approaches (Rasbash et al., 2009). The first model examined the extent to which overall vulnerability of kindergarten children with ASD varied across neighbourhoods. The second model included demographic characteristics (child's sex, age, having English/French as a second language (E/FSL)) and family SES (marital status, education, language/immigration, residential stability) of kindergarten children with ASD at level one in province specific analyses, and in the pan-Canadian analyses. In the pan-Canadian analyses, the second model also included a variable indicating these children's province of residence at level one. The third model included neighbourhood SES (neighbourhood SES index score for 2011) at level two. For the second and third models, all predictor variables at level one and two were entered as fixed effects, meaning their associations were constrained to be constant across neighbourhoods. Predictor variables were not centered as the purpose of centering is to ensure the intercept reflects the 'average' child, whereas the purpose of the multilevel models in this study was to identify the magnitude of association between



neighbourhood SES and developmental vulnerability without focusing on the intercept. A marginal quasi-likelihood (MQL) estimation process was used to create the models. The MQL estimation process uses a linearization method and is used to transform a discrete response model to a continuous response model in multilevel analyses (Goldstein, 2003). Similar multilevel binary logistic regression analyses were used to examine the association between neighbourhood SES and developmental vulnerability on each of the EDI domains at the individual level, while controlling for demographic characteristics, family SES, and neighbourhood clustering.

Binary single level logistic regression analyses were used to examine the association between neighbourhood SES with overall vulnerability and developmental vulnerability on each of the EDI domains, while controlling for demographic characteristics and family SES. There is evidence indicating that the sample size guideline for logistic regression analyses, which requires at least 10 events per predictor in the model, may be too conservative (Vittinghoff & McCulloch, 2007). In this context, the sample size guideline for linear regression analyses, which requires 10 to 20 observations per predictor in a model, was used for the logistic regression analyses in this study (Harrell, 2011). Thus, provinces with at least 80 kindergarten children with ASD that were excluded from the multilevel analyses were included in the single level binary logistic regression analyses. Provinces included in these logistic regression analyses for each of the vulnerability outcomes differed based on these sample size requirements.

Multivariable linear regression analyses were used to examine the association between neighbourhood SES and developmental vulnerability at the neighbourhood level

(% of kindergarten children with ASD demonstrating vulnerability on each of the EDI domains and overall vulnerability in a neighbourhood), while controlling for neighbourhood demographic characteristics (% of male kindergarten children with ASD, average age of kindergarten children with ASD, % of kindergarten children with E/FSL status in a neighbourhood), family SES (% separated, divorced, or widowed, % above 15 years with no secondary diploma, % not speaking either official language at home, % of population who moved during the past 5 years in a neighbourhood), as well as spatial cluster level of kindergarten children with ASD in neighbourhoods (neighbourhoods with one, two, three, four, five, and six or more kindergarten children with ASD). Since 10 to 20 observations are needed per predictor in a linear regression model, at least 90 neighbourhoods were needed for these linear regression analyses and only provinces that met this sample size criterion were included (Ontario, Alberta, British Columbia, and Quebec) (Harrell, 2011).

## ***2.7 Ethics***

Ethics approval for this study was obtained from the Hamilton Integrated Research Ethics Board.

## **3. Theory**

The “ecological model” of child development proposed by Bronfenbrenner was used to inform this study. This model encapsulates the different levels of influence on child development and presents a nuanced framework to study individual, neighbourhood, and regional factors in relation to children’s health (Adler et al., 1994; Hertzman, 1999).

This study contributes to the literature by using the ecological model to focus on health of children with mental disorders, as this model has been largely used in the context of physical disorders (Siddiqua, Duku, Georgiades, Mesterman, & Janus, 2019).

#### **4. Results**

Since only kindergarten children with ASD are included in the sample, to simplify the language they will be sometimes referred to in this Results section only as “children”.

##### ***4.1 Developmental vulnerability of children with ASD***

The average proportions, by province and territory in the study, of kindergarten children with ASD who demonstrated overall vulnerability across neighbourhoods with different levels of spatial clusters (with one<sup>1</sup>, two, three, four, five, and six or more) are presented in Table 2.

Across provinces and territories, the average proportions of children with ASD who demonstrated overall vulnerability across neighbourhoods with one child with ASD ranged from 75% to 100%. Across provinces and territories, the proportions of neighbourhoods with one child with ASD where the child demonstrated overall vulnerability ranged from 75% to 100% (Appendix 3). The average proportions of children with ASD who demonstrated overall vulnerability in neighbourhoods with higher levels of spatial clusters were: in neighbourhoods with two children with ASD, 57.1% to

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<sup>1</sup> Average proportion of vulnerability for neighbourhoods with one child with ASD are provided to maintain consistency in results from neighbourhoods with higher levels of spatial clusters of children with this disorder and are not to be interpreted.

100%; in neighbourhoods with three children with ASD, 77.8% to 90.5%; in neighbourhoods with four children with ASD, 75% to 100%; in neighbourhoods with five children with ASD, 71.4% to 100%; and in neighbourhoods with 6 or more children with ASD, 70.9% to 90.1%.

When vulnerability in specific areas of development was explored, there were no consistent trends in any EDI domains for either lowest or highest average proportion of children with ASD demonstrating vulnerability in neighbourhoods with each level of spatial cluster across provinces and territories (Appendices 4 to 8). Although the trends in vulnerability across spatial clusters as the number of children with ASD increased in a neighbourhood were statistically linear in the majority of provinces and territories, the magnitude of vulnerability as the number of children with ASD increased in a neighbourhood did not consistently decrease for overall vulnerability and different areas of development.

#### ***4.2 Neighbourhood SES and developmental vulnerability: Multilevel models of overall and domain-specific vulnerability***

Table 3 shows the extent to which developmental vulnerability varied across neighbourhoods. The between-neighbourhood variation in *overall vulnerability* in children with ASD was 1.6% and 5.5% of the total variation in overall vulnerability, in pan-Canadian analysis # 1 and pan-Canadian analysis # 2, respectively. The between-neighbourhood variation in *vulnerability in specific areas of development* ranged from 2.2% to 5.4% of the total variation in vulnerability, in the Emotional Maturity and

Communication Skills and General Knowledge domains, respectively. In pan-Canadian analysis # 2, between-neighbourhood variation in vulnerability ranged from 2.1% in the Physical Health and Well-Being domain to 4.8% in the Communication Skills and General Knowledge domain. In the province specific analysis, the between-neighbourhood variation in *overall vulnerability* ranged from 0% in Manitoba, Alberta, Nova Scotia, and Quebec to 14% in British Columbia. For *vulnerability in specific areas of development*, the following intervals were observed: Physical Health and Well-Being domain, from 0% in Manitoba to 6% in Alberta; Social Competence domain, from 0% in Manitoba to 8% in British Columbia; Emotional Maturity domain, from 0% in Manitoba and Quebec to 8% in British Columbia; Language and Cognitive Development domain, from 2% in Alberta and Nova Scotia to 4% in Ontario and Manitoba; and Communication Skills and General Knowledge domain, from 0% in Manitoba to 7% in Alberta.

In pan-Canadian analysis # 1, higher neighbourhood SES was associated with lower odds of *overall vulnerability* (OR: 0.89, 95% CI: 0.80, 0.98;  $p < 0.05$ ) (Table 4). Similar trends were observed when the associations between neighbourhood SES and *vulnerability in specific areas of development* were explored (Appendices 9 to 13). In pan-Canadian analysis # 2, no statistically significant association between neighbourhood SES and developmental vulnerability outcomes was observed.

In province-specific analysis, higher neighbourhood SES was associated with lower odds of *overall vulnerability* in Ontario (OR: 0.86, 95% CI: 0.75, 0.98;  $p < 0.05$ ) and British Columbia (OR: 0.69, 95% CI: 0.52, 0.94,  $p < 0.05$ ) (Table 4). When the association between neighbourhood SES and *vulnerability in specific areas of development* was

explored, a similar trend was observed in several provinces (Appendices 9 to 13). Higher neighbourhood SES was associated with lower odds of vulnerability in the Physical Health and Well-Being domain in Ontario (OR: 0.90, 95% CI: 0.83 to 0.99;  $p < 0.05$ ). Higher neighbourhood SES was associated with lower odds of vulnerability in the Social Competence domain in Ontario (OR: 0.89, 95% CI: 0.81 to 0.98;  $p < 0.05$ ). Higher neighbourhood SES was associated with lower odds of vulnerability in the Emotional Maturity domain in British Columbia (OR: 0.73, 95% CI: 0.58 to 0.91;  $p < 0.05$ ). It should be noted that the multilevel model conducted for the Emotional Maturity domain in Nova Scotia was modified to exclude E/FSL status, as the model did not converge when this variable was included, likely due to the fact that majority of children with ASD in Nova Scotia did not have E/EFSL status (97.45%). Higher neighbourhood SES was associated with lower odds of vulnerability in the Language and Cognitive Development domain in Ontario (OR: 0.87, 95% CI: 0.79 to 0.95;  $p < 0.01$ ), and in Manitoba (OR: 0.74, 95% CI: 0.55 to 0.99;  $p < 0.05$ ). Higher neighbourhood SES was associated with lower odds of vulnerability in the Communication Skills and General Knowledge domain in Ontario (OR: 0.86, 95% CI: 0.78 to 0.94;  $p < 0.01$ ). In Nova Scotia only, higher neighbourhood SES was associated with higher odds of vulnerability in the Social Competence domain (OR: 2.13, 95% CI: 1.14 to 4.01,  $p < 0.05$ ) and in the Communication Skills and General Knowledge domain (OR: 2.25, 95% CI: 1.14 to 4.43;  $p < 0.05$ ).

#### ***4.3 Neighbourhood SES and developmental vulnerability: Individual single level model***

Due to sample size requirements described earlier, a different set of provinces was included in the logistic regression analyses for each of the developmental vulnerability

outcomes (Table 5 and Appendices 14 to 18). Higher neighbourhood SES was associated with lower odds of vulnerability in the Physical Health and Well-Being domain in Newfoundland and Labrador (OR: 0.54, 95% CI: 0.33 to 0.88;  $p < 0.05$ ) (Appendix 14).

#### ***4.4 Neighbourhood SES and developmental vulnerability: Neighbourhood level model***

Most jurisdictions had fewer than 90 neighbourhoods present, hence multivariable linear regression analyses were performed only for Ontario, Alberta, British Columbia, and Quebec. Higher neighbourhood SES was associated with lower percentage of children with ASD with overall vulnerability in Ontario ( $\beta$ : -2.90, 95% CI: -4.82 to -0.98;  $p < 0.01$ ) (Table 6). Higher neighbourhood SES was also associated with lower percentage of children with ASD with vulnerability in the domains of Social Competence ( $\beta$ : -3.68, 95% CI: -6.67 to -0.69;  $p < 0.05$ ), Language and Cognitive Development ( $\beta$ : -5.22, 95% CI: -8.23 to -2.16;  $p < 0.01$ ), and Communication Skills and General Knowledge ( $\beta$ : -4.61, 95% CI: -7.38 to -1.83;  $p < 0.01$ ) in Ontario (Appendices 19 to 23).

## **5. Discussion**

Our study showed that the average proportions of kindergarten children with ASD demonstrating vulnerability overall and in specific areas of development were generally high across provinces and territories. Notably, these proportions did not consistently decrease with increase in size of spatial clustering of children with ASD per neighbourhood as hypothesized, even though the average proportions of vulnerable children with ASD in each level of spatial cluster were still high. The minimum average proportion of kindergarten children with ASD demonstrating overall vulnerability was

57.1% and the maximum average proportion of these children demonstrating overall vulnerability was 100% for all neighbourhoods. These findings complement current literature which suggests that despite the increased susceptibility of children with ASD to developmental vulnerabilities, there can be significant heterogeneity in their developmental pathways from youth to early adulthood age (Fountain et al., 2012; Szatmari et al., 2015; Lord, Bishop, & Anderson, 2015).

Approximately 5-10% of the variation in children's development, well-being, and health can be explained by neighbourhood factors (Sellstrom & Bremberg, 2006); moreover, better health or education outcomes are observed among children who live in wealthier areas (Martens et al., 2004). There is also some evidence that higher neighbourhood SES may have diminishing rates of return on supporting enhanced child development (Carpiano et al., 2009). Carpiano et al. showed that kindergarten children's highest average scores in four EDI domains (Physical Health and Well-Being, Social Competence, Emotional Maturity, and Communication Skills and General Knowledge) were not found in neighbourhoods with highest SES, but rather in neighbourhoods where there were approximately equal proportions of affluent and disadvantaged families. A recent study shows that kindergarten children with special needs who live in high SES neighbourhoods have better developmental outcomes than those who live in lower SES neighbourhoods (Zeraatkar et al., 2020). The results of our study showed that in higher SES neighbourhoods, kindergarten children with ASD were generally less likely to demonstrate vulnerability.



It is useful to separate out neighbourhood effects from influences of individual and family characteristics when studying health effects of neighbourhood SES in order to inform interventions for social groups that have limited resources (Sellstrom & Bremberg, 2006) which can be achieved with the multilevel modelling approach. In our analyses (the #1 pan-Canadian approach), higher neighbourhood SES was associated with lower likelihood of developmental vulnerability, while controlling for clustering, province, and individual demographics. This indicates that neighbourhood SES seems to have a pan-Canadian impact on development of children with ASD regardless of the province of residence, despite different provincial health policies and systems in place that influence early identification and services.

In the province specific multilevel analyses, higher neighbourhood SES was also associated with lower likelihood of demonstrating developmental vulnerability, including overall vulnerability and vulnerability in all the areas of development in several provinces. However, in Ontario, this trend was consistently observed in four areas of development (Physical Health and Well-Being, Social Competence, Language and Cognitive Development, and Communication Skills and General Knowledge). These findings indicate that neighbourhood SES has an independent effect on developmental vulnerability of kindergarten children with ASD, reflecting results of a number of studies that showed neighbourhood deprivation was associated with poor child development (e.g., Safra et al., 2016; Kalff et al., 2001). These findings also complement current literature which indicates that living in disadvantaged neighbourhoods represents an independent risk factor for health of children, even when controlling for individual

demographic and socioeconomic characteristics (Schneiders et al., 2003). Both neighbourhood and family mechanisms are considered to play an important role in transmitting neighbourhood socioeconomic effects (Pickett & Pearl, 2001; Kohen, Dahinten, Leventhal, & McIntosh, 2008). For example, Kohen et al. (2008) found that neighbourhood socioeconomic disadvantage manifested its effect on young children through lower neighbourhood cohesion, which was associated with maternal depression and family dysfunction. These mechanisms were in turn related to less stimulating and more punitive parenting behaviour and ultimately poor outcomes in children. In contrast, in Nova Scotia only, higher neighbourhood SES was associated with higher likelihood of demonstrating vulnerability in two areas of development (Social Competence and Communication Skills and General Knowledge). This highlights the importance of examining the mechanisms through which neighbourhood SES impacts development of children with ASD on a provincial basis, as although neighbourhood deprivation is generally associated with poor development, this was not the case for the province of Nova Scotia.

The region-specific analyses showed inconsistencies across the country in the patterns of association between neighbourhood SES and vulnerability of children with ASD in specific domains. Specifically, only in Newfoundland and Labrador, higher neighbourhood SES was associated with lower likelihood of demonstrating vulnerability in the Physical Health and Well-Being domain at the individual level. Only in Ontario, higher neighbourhood SES was associated with lower percentage of kindergarten children with ASD demonstrating overall vulnerability and vulnerability in specific areas of

development at the neighbourhood level. Taken together with the results of the multilevel analyses, results of the individual and neighbourhood level analyses emphasize two main points. First, consideration of neighbourhood characteristics when addressing the needs of young children with ASD is relevant. Second, the incidence levels guiding intervention need to be considered, as the type and location of interventions will be different if individual cases versus neighbourhood clustering of cases are considered. In order to address the socioeconomic gradient in development of children with ASD, a proportionate universalism approach can be taken to implement interventions – where interventions will be universal for children with this disorder, but the scale and intensity of these interventions will be proportionate to the level of disadvantage they experience in their development as a function of their neighbourhood SES (Carey, Crammond, & Leeuw, 2015).

There are several limitations of this study. Implementation of the EDI did not occur every year from 2010 to 2015 in every province and territory, with more implementations occurring in some provinces and territories compared to others, which could have influenced the estimates of numbers of kindergarten children with ASD at the neighbourhood level. No formal evaluation yet has been conducted to evaluate the reliability of the diagnosis reported on the EDI compared to data from health services based on ‘gold standard’ diagnostic procedures for ASD. However, the reliability of the EDI data as a source of ASD diagnosis can be ascertained through several points. First, findings from Manitoba and Ontario show there is fair concordance between EDI and population-level administrative data when identifying children with ASD (Reid-Westoby,

Horner, & Janus, 2018). Second, teachers report medical diagnoses on the EDI based on identification by accredited external health professionals (doctor or psychological professional), as per information shared by parents with the school. Third, social bias in case detection may not be a limitation of educational sources such as the EDI.

Nonetheless, it is possible that ASD diagnosis is subject to over- or under-reporting, which may differ by place of residence across the country. Although the multilevel analytical approach considers the similarity of kindergarten children with ASD in a neighbourhood, it is possible that a portion of the estimated effect of neighbourhood deprivation in the models may be attributable to individual level effects, which would be the case if families with particular unmeasured characteristics were more likely to live in disadvantaged than in advantaged neighbourhoods (Schneiders et al., 2003). Last, we used small area level SES as a proxy for family SES, where not everyone living in that area may have the same SES.

There are also several strengths of this study. As a large population-level database, the EDI demonstrates significant utility from a public health perspective. Until now, there was no population-wide database with which the objectives of this study could be investigated – specifically separate impact of individual and neighbourhood characteristics on health of kindergarten children with ASD. The use of the large EDI database presents an unprecedented opportunity to examine the developmental vulnerability of kindergarten children with ASD in neighbourhoods with different levels of spatial clusters of these children, as well as the association between neighbourhood SES and children’s developmental vulnerability across provinces and territories in

Canada. This analysis was not possible through sample-based research where children with ASD are commonly not available or included in sufficient numbers. The nation-wide implementation of the EDI provides a large representative sample, improving generalizability of study findings. Using a composite SES index, that has shown relevant associations with development of young children, was also a strength as it captures the favourable and unfavourable SES characteristics of neighbourhoods through a reasonable number of variables (Forer et al. 2019; Webb et al., 2017). The human, social, economic components of this index, all of which are important elements of SES, are not collectively included in other neighbourhood SES indices derived using Canadian Census data (Webb et al., 2017).

## **6. Conclusions**

Findings of this study emphasize the importance of addressing neighbourhood disadvantage to support the development of kindergarten children with ASD. Our study showed that the impact of neighbourhood SES on development of these children varies across provinces and territories, highlighting the importance of customized service planning.

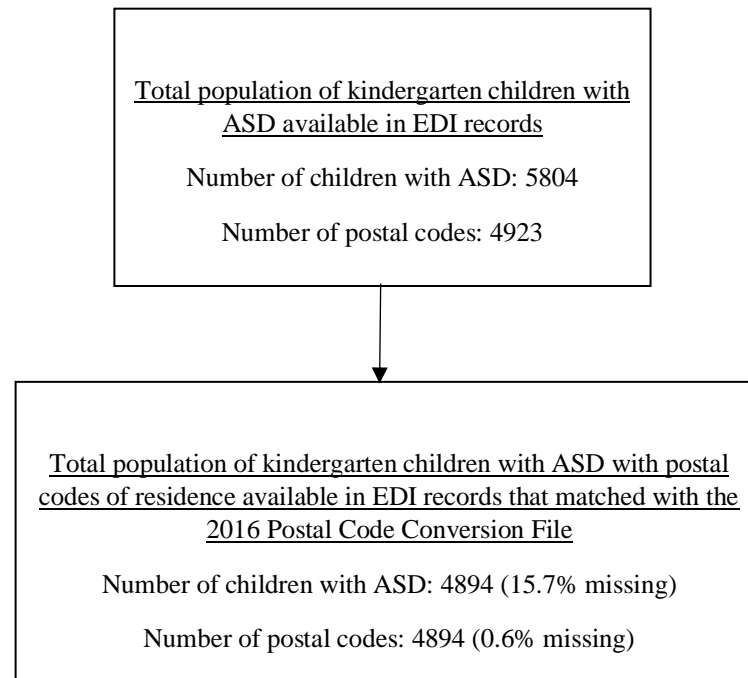


Figure 1: Flowchart of sample of kindergarten children with ASD included in the study

Table 1

*Census and Income Taxfiler components for examining neighbourhood and individual SES*

Variables in Neighbourhood SES Index	
Marital Status*	Percent separated or divorced
Education*	Percent of those 25 to 64 with no high school diploma
Language/Immigration*	Percent whose home language is a non-official language
Residential Stability*	Percent of individuals, non-migrant movers in the past year
High Income	Percent at or exceeding twice the median provincial income, families with children under 6
Poverty	Percent below Low Income Measure, lone parents with children under 6
Dues	Percent deducting dues, families with children under 6
Social Capital	Percent families declaring charitable donations, families with children under 6
Wealth	Percent families with investment income or capital gains, families with children under 6
Income Inequality	GINI coefficient quintiles (income inequality), lone female parents with children under 6
Variables used as proxies for Individual SES variables	
Marital Status**	Percent separated, divorced, or widowed
Education**	Percent above 15 years with no secondary diploma
Language/Immigration**	Percent not speaking either official language at home
Residential Stability**	Percent of population who moved during the past 5 years

\*Variables included in 2006 and 2011 Canadian Census; \*\*Variables included in 2016 Canadian Census

Table 2

*Overall vulnerability at the neighbourhood level of kindergarten children with ASD living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1	89.6	30.7	75.0	45.2	85.9	35.0	88.9	31.7	92.9	26.7			100	.0	80.0	44.7	100.0	.0	79.3	40.7
2	91.3	21.0	100.0	.0	91.0	19.4	90.8	19.6	57.1	34.5			83.3	28.9	91.7	20.4	100.0	.0	72.7	31.8
3	90.5	17.8	79.2	17.3	81.3	23.9	88.2	20.0	88.9	19.2	83.3	23.6	85.7	26.2	88.9	16.7			76.7	27.2
4	91.6	15.6	90.6	12.9	87.5	18.9	88.3	21.0	91.7	14.4	100.0	.	75.0	25.0	87.5	20.9			77.1	22.5
5	86.1	16.7	90.0	16.7	90.0	10.5	90.5	13.6	95.0	10.0			75.0	30.0	80.0		100.0		71.4	19.5
6 or more	87.3	12.5	87.4	10.5	82.4	10.2	88.2	13.4	84.7	2.4			79.6	12.8	89.9	10.8			70.9	15.4

\* $p > 0.05$  for linearity tests for all provinces, with the exception of Northwest Territories and Yukon. Linearity test was not conducted for Northwest Territories as there were fewer than 3 levels of spatial clusters of kindergarten children with ASD, as well as for Yukon as there was no variance within the spatial clusters.



Table 3

*Intraclass Correlation Coefficients examining the extent to which vulnerability on each EDI domain and overall vulnerability among kindergarten children with ASD vary between neighbourhoods*

	Pan-Canadian Analysis # 1	Pan-Canadian Analysis # 2	Ontario	Manitoba	Alberta	British Columbia	Nova Scotia	Quebec
Overall vulnerability	1.6%	5.5%	5%	0%	0%	14%	0%	0%
Vulnerability on Physical Health and Well-Being domain	2.3%	2.1%	2%	0%	6%	3%	1%	0%
Vulnerability on Social Competence domain	3.9%	4.3%	4%	0%	5%	8%	5%	0.1%
Vulnerability on Emotional Maturity domain	2.2%	3.7%	2%	0%	6%	8%	2%	0%
Vulnerability on Language and Cognitive Development domain	4.1%	3.3%	4%	4%	2%	4%	2%	2.8%
Vulnerability on Communication Skills and General Knowledge domain	5.4%	4.8%	6%	0%	7%	5%	5%	0.6%

Pan-Canadian Analysis # 1: Includes 6 provinces (Ontario, Manitoba, Alberta, British Columbia, Nova Scotia, Quebec); Pan-Canadian Analysis # 2: Includes 8 provinces (Ontario, British Columbia, Quebec, Prairies (Alberta, Saskatchewan, Manitoba), Atlantic provinces (Nova Scotia, Newfoundland))

\*Intraclass Correlation Coefficients have been converted to percentages to report amount of unexplained variation in outcomes attributed to grouping variable

Table 4

*Predictors of overall vulnerability among kindergarten children with ASD after accounting for clustering by neighbourhoods*

Variable	Classification	Pan-Canadian Analysis # 1		Pan-Canadian Analysis # 2		Ontario		British Columbia	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics									
Age		0.87	0.70, 1.08	0.87	0.57, 1.32	0.69*	0.50, 0.97	1.80	0.99, 3.32
Sex (Female)	Male	1.40**	1.15, 1.72	1.47	0.99, 2.17	1.15	0.87, 1.53	1.45	0.83, 2.53
EFSL status (No)	Yes	2.12	1.51, 2.96	1.68	0.81, 3.50	2.49*	1.53, 4.38	2.39*	1.07, 5.37
Province (Ontario)‡	Manitoba	0.85	0.59, 1.23						
	Alberta	0.79	0.59, 1.05						
	British Columbia	0.98	0.77, 1.25						
	Nova Scotia	1.12	0.73, 1.71						
	Quebec	0.45	0.34, 0.59						
Province (Ontario)†	British Columbia			-	-				
	Quebec			-	-				
	Prairies (Alberta, Saskatchewan, Manitoba)			-	-				
	Atlantic provinces (Nova Scotia, Newfoundland)			0.59*	0.39, 0.89				
Marital status		1.11*	1.01, 1.23	1.15	0.92, 1.43	1.23**	1.07, 1.43	0.89	0.68, 1.34
Education		1.13*	1.01, 1.27	1.04	0.85, 1.28	0.98	0.83, 1.16	1.51*	1.03, 2.23
Language/Immigration		1.07	0.96, 1.18	0.89	0.72, 1.09	1.11	0.97, 1.26	0.93	0.74, 1.19
Residential Stability		1.02	0.94, 1.12	1.09	0.92, 1.29	0.92	0.82, 1.03	1.29	0.96, 1.65

Neighbourhood characteristics													
Neighbourhood SES Index		0.89*	0.80, 0.98	0.90	0.71, 1.14	0.86*	0.75, 0.98	0.69*	0.52, 0.94				

\*p<0.05; \*\*p<0.01; ‡Province variable only pertains to Pan-Canadian Analysis # 1; †Province variable only pertains to Pan-Canadian Analysis # 2

Table 5

*Predictors of overall vulnerability among kindergarten children with ASD*

Variable	Classification	Manitoba		Alberta		Saskatchewan		Newfoundland		Nova Scotia		Quebec	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics													
Age		0.89	0.40, 2.00	0.62	0.33, 1.15	1.72	0.37, 7.99	1.30	0.57, 2.99	0.66	0.26, 1.68	1.11	0.61, 2.02
Sex (Female)	Male	0.50	0.21, 1.17	0.80	0.39, 1.64	0.44	0.11, 1.76	0.52	0.22, 1.20	0.32*	0.14, 0.77	0.50*	0.29, 0.88
EFSL status (No)	Yes	4.09	0.52, 32.21	0.42	0.12, 1.44	0	0, 0	1.54	0.13, 18.35	0.84	0.09, 8.11	0.70	0.34, 1.43
Marital status		1.15	0.77, 1.71	1.22	0.87, 1.70	1.09	0.57, 2.07	1.24	0.72, 2.13	0.65	0.39, 1.10	1.06	0.79, 1.43
Education		1.23	0.83, 1.83	1.12	0.77, 1.63	1.29	0.60, 2.76	0.89	0.64, 1.23	1.57	0.91, 2.71	1.20	0.91, 1.57
Language/Immigration		1.43	0.73, 2.77	1.27	0.84, 1.93	1.84	0.22, 15.70	0.05*	0.00, 0.82	17.20	0.04, 7049.93	1.08	0.75, 1.56
Residential Stability		0.77*	0.51, 0.99	1.41*	1.07, 1.86	1.08	0.55, 2.13	1.25	0.83, 1.89	1.71	0.99, 2.94	1.12	0.87, 1.46
Neighbourhood characteristics													
Neighbourhood SES Index		0.98	0.66, 1.50	1.21	0.86, 1.71	1.00	0.43, 2.29	0.80	0.45, 1.44	1.75	0.63, 4.82	0.97	0.74, 1.26

\*p<0.05

Table 6

*Predictors of proportion of kindergarten children with ASD with overall vulnerability in a neighbourhood*

Neighbourhood characteristics	Ontario		Alberta		British Columbia		Quebec	
	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI
Mean age	1.38	-5.13, 7.90	-0.95	-10.29, 8.38	7.97	-2.07, 18.02	4.74	-8.62, 18.11
% male	-0.01	-0.06, 0.05	-0.05	-0.21, 0.11	0.06	-0.05, 0.16	0.22**	0.08, 0.37
% EFSL	0.07	-0.01, 0.15	0.10	-0.10, 0.30	0.14	0.00, 0.28	0.01	-0.16, 0.62
Mean % separated, divorced, or widowed	-0.37	-2.58, 1.84	-0.55	-5.86, 4.77	-0.83	-4.84, 3.19	1.65	-5.35, 8.65
Mean % above 15 years with no secondary diploma	0.49	-1.98, 2.96	2.88	-2.50, 8.26	6.54**	1.72, 11.37	2.75	-3.04, 8.53
Mean % not speaking either official language at home	0.59	-1.17, 2.35	0.30	-6.24, 6.84	-2.03	-5.65, 1.59	1.51	-6.86, 9.88
Mean % of population who moved during the past 5 years	-0.56	-2.70, 1.59	4.35	-0.76, 9.46	2.09	-2.13, 6.31	4.14	-5.12, 1.33
Number of kindergarten children with ASD in a neighbourhood	-0.83*	-1.62, -0.03	-0.57	-3.11, 1.96	-0.03	-1.66, 1.60	-1.89	-5.12, 1.33
Neighbourhood SES Index	-2.90**	-4.82, -0.98	1.70	-3.70, 7.09	-1.23	-5.23, 2.77	-1.00	-6.95, 4.95

\*p<0.05; \*\*p<0.01

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Appendix 1

*Implementation of EDI across provinces and territories in Canada from 2010 to 2015*

	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	New Brunswick	Prince Edward Island	Quebec	Nunavut
2010	32184	0	17413	24671	8167	0	0	756	340	0	0	0	0
2011	37494	11841	17955	21767	5151	0	1088	2317	341	0	0	0	0
2012	55257	0	12710	12406	539	585	2090	2198	365	0	0	65042	0
2013	0	12886	16541	29854	7955	623	4835	8398	399	0	0	0	0
2014	0	0	0	1277	0	613	5069	1376	0	0	0	0	0
2015	132873	13224	0	0	0	602	0	8513	0	0	0	0	0

Appendix 2

*Number of kindergarten children with ASD with individual level socioeconomic information available*

	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
Number of children with ASD	n=3074	n=301	n=472	n=856	n=89	n=10	n=213	n=277	n=12	n=500
Number of children with ASD with individual socioeconomic information available	3053	301	466	856	88	10	213	268	12	451

Appendix 3

*Proportion of neighbourhoods with one child with ASD where child demonstrated overall vulnerability*

	Ontario	Manitoba	Alberta	British Columbia	Saskatchewan	Northwest Territories	Newfoundland and Labrador	Nova Scotia	Yukon	Quebec
Number of neighbourhoods with 1 child with ASD	n=115	n=12	n=64	n=63	n=14	n=0	n=1	n=5	n=1	n=116
Neighbourhoods with 1 child with ASD where child demonstrated overall vulnerability n (%)	103 (89.6)	9 (75)	55 (85.9)	56 (88.9)	13 (92.9)		1 (100)	4 (80)	1 (100)	92 (79.3)

Appendix 4

*Vulnerability on Physical Health and Well-Being Domain at the neighbourhood level of kindergarten children with ASD living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1	63.2	48.5	33.3	49.2	59.4	49.5	65.1	48.1	64.3	49.7			100		60.0	54.8	.0		38.8	48.9
2	54.3	36.7	75.0	26.7	65.0	36.8	54.1	32.0	50.0	40.8			66.7	28.9	83.3	25.8	66.7	28.9	28.0	27.9

3	54.9	28.7	50.0	17.8	52.6	31.4	60.4	31.3	66.7	.0	66.7	47.1	66.7	33.3	55.6	37.3		26.7	25.5
4	56.8	25.6	68.8	17.8	60.4	28.4	68.5	23.7	75.0	.0	50.0		41.7	38.2	65.3	25.5		33.3	22.2
5	50.7	24.2	60.0	12.6	62.0	29.0	59.8	22.6	55.0	34.2			35.0	25.2	60.0		100.0	31.4	15.7
6 or more	50.8	19.2	64.2	15.3	50.1	18.9	61.0	20.0	66.7	16.7			38.4	20.0	50.2	16.3		24.6	16.8

\* $p > 0.05$  for linearity tests for all provinces, with the exception of Manitoba, where  $p < 0.05$ . Linearity test was not conducted for Northwest Territories as there were fewer than 3 levels of spatial clusters of kindergarten children with ASD.

### Appendix 5

#### *Vulnerability on Social Competence Domain at the neighbourhood level of kindergarten children with ASD living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec		
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	
1	67.8	46.9	66.7	49.2	63.5	48.5	67.7	47.1	64.3	49.7			100.0		75.0	50.0	.0			46.6	50.1
2	68.5	33.2	68.8	37.2	77.0	27.1	72.9	32.5	50.0	40.8			66.7	28.9	75.0	27.4	66.7	28.9		39.4	34.5
3	68.5	29.8	75.0	15.4	60.4	29.9	67.7	30.8	77.8	19.2	66.7	.0	66.7	33.3	77.8	28.9				48.6	39.3
4	71.5	24.2	68.8	32.0	74.0	19.1	73.2	24.6	83.3	28.9	75.0		58.3	38.2	62.5	20.9				47.9	29.1
5	64.1	26.6	63.3	8.2	66.0	23.2	69.0	22.3	65.0	30.0			63.8	29.3	20.0		80.0			40.0	23.1
6 or more	67.5	17.6	69.4	14.2	58.0	21.7	65.4	21.1	65.8	19.4			60.3	14.1	67.4	19.5				41.5	17.5

\* $p > 0.05$  for linearity tests for all provinces, with the exception of Northwest Territories. Linearity test was not conducted for Northwest Territories as there were fewer than 3 levels of spatial clusters of kindergarten children with ASD.

Appendix 6

*Vulnerability on Emotional Maturity Domain at the neighbourhood level of kindergarten children with ASD living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1	70.8	45.7	66.7	49.2	70.3	46.0	61.7	49.0	78.6	42.6			100.0		80.0	44.7	.0		62.9	48.5
2	75.2	31.4	68.8	37.2	74.0	33.9	74.0	34.2	50.0	28.9			83.3	28.9	83.3	25.8	66.7	28.9	53.8	36.5
3	74.3	27.0	68.8	13.9	61.5	29.5	67.7	30.8	77.8	19.2	66.7	47.1	71.4	40.5	70.4	30.9			58.3	26.5
4	73.2	23.9	78.1	16.0	71.9	24.8	74.2	30.1	75.0	25.0	75.0		41.7	28.9	66.7	12.9			59.0	26.0
5	70.1	22.8	66.7	20.7	66.0	25.0	74.0	19.1	70.0	20.0			65.0	19.1	60.0		80.0		58.6	23.4
6 or more	68.1	17.2	73.9	14.2	65.0	20.9	71.3	19.0	55.6	9.6			61.8	14.5	66.5	18.1			53.2	16.5

\* $p > 0.05$  for linearity tests for all provinces, with the exception of Northwest Territories. Linearity test was not conducted for Northwest Territories as there were fewer than 3 levels of spatial clusters of kindergarten children with ASD.

Appendix 7

*Vulnerability on Language and Cognitive Development Domain at the neighbourhood level of kindergarten children with ASD living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1	40.4	49.3	25.0	45.2	48.4	50.4	46.8	50.3	42.9	51.4			100.0		40.0	54.8	.0		26.7	44.4
2	37.8	36.0	62.5	44.3	46.0	36.2	40.8	34.9	35.7	37.8			16.7	28.9	50.0	.0	16.7	28.9	29.5	30.4
3	39.7	29.0	62.5	33.0	43.8	33.3	39.2	31.0	77.8	19.2	66.7	.0	42.9	31.7	29.6	26.1			42.0	32.3
4	37.6	27.2	53.1	28.1	32.3	25.8	42.4	27.9	63.9	12.7	.0		25.0	25.0	50.0	15.8			37.5	25.0

5	36.3	24.3	43.3	15.1	38.0	17.5	40.0	28.3	40.0	28.3		50.0	25.8	20.0	.	25.0		22.9	21.4
6 or more	35.3	19.4	48.0	20.7	34.8	16.2	38.1	19.7	46.7	5.8		24.7	14.6	38.3	20.6			16.7	16.3

\* $p > 0.05$  for linearity tests for all provinces, with the exception of Newfoundland and Labrador, where  $p < 0.05$ . Linearity test was not conducted for Northwest Territories as there were fewer than 3 levels of spatial clusters of kindergarten children with ASD.

### Appendix 8

*Vulnerability on Communication Skills and General Knowledge Domain at the neighbourhood level of kindergarten children with ASD living in neighbourhoods with different levels of spatial clusters of kindergarten children with ASD*

Number of kindergarten children with ASD in a neighbourhood	Ontario		Manitoba		Alberta		British Columbia		Saskatchewan		Northwest Territories		Newfoundland and Labrador		Nova Scotia		Yukon		Quebec	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1	79.1	40.8	41.7	51.5	65.6	47.9	76.2	42.9	71.4	46.9			100.0		80.0	44.7	100.0		48.3	50.2
2	69.3	35.1	93.8	17.7	76.0	30.7	69.4	35.1	42.9	34.5			83.3	28.9	75.0	27.4	50.0	50.0	38.6	32.6
3	71.2	27.4	70.8	27.8	74.0	25.0	69.4	29.0	77.8	19.2	83.3	23.6	76.2	31.7	77.8	23.6			52.7	30.3
4	71.7	25.8	65.6	29.7	52.1	35.8	66.9	30.7	75.0	25.0	25.0		58.3	28.9	79.2	18.8			41.7	22.2
5	66.1	21.4	76.7	15.1	68.0	25.3	70.5	21.6	80.0	28.3			75.0	30.0	20.0	.	75.0		40.0	23.1
6 or more	67.7	19.6	75.1	12.0	59.3	20.6	67.1	17.1	63.9	26.8			58.0	17.1	65.1	19.5			38.3	24.5

\* $p > 0.05$  for linearity tests for all provinces, with the exception of Manitoba, where  $p < 0.05$ . Linearity test was not conducted for Northwest Territories as there were fewer than 3 levels of spatial clusters of kindergarten children with ASD.

Appendix 9

*Predictors of vulnerability on the Physical Health and Well-Being domain among kindergarten children with ASD after accounting for clustering by neighbourhoods*

Variable	Classification	Pan-Canadian Analysis # 1		Pan-Canadian Analysis # 2		Ontario		Alberta		British Columbia		Nova Scotia	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>Individual characteristics</b>													
Age		0.79**	0.68, 0.92	0.79	0.59, 1.05	0.71**	0.57, 0.89	0.65	0.41, 1.01	0.65	0.41, 1.01	0.68	0.39, 1.20
Sex (Female)	Male	1.01	0.87, 1.17	1.05	0.79, 1.39	0.95	0.79, 1.14	0.75	0.43, 1.31	0.75	0.43, 1.31	1.01	0.55, 1.86
EFSL status (No)	Yes	1.38**	1.15, 1.66	0.87	0.58, 1.32	1.32*	1.03, 1.68	1.97	0.97, 4.01	1.97	0.97, 4.01	0.64	0.14, 3.01
Province (Ontario)‡	Manitoba	1.30*	1.01, 1.68										
	Alberta	1.15	0.94, 1.42										
	British Columbia	1.40*	1.19, 1.64										
	Nova Scotia	0.97	0.74, 1.26										
	Quebec	0.43*	0.34, 0.54										
Province (Ontario)†	British Columbia			-	-								
	Quebec			-	-								
	Prairies (Alberta, Saskatchewan, Manitoba)			-	-								



	Atlantic provinces (Nova Scotia, Newfoundland)			0.54, 0.93									
Marital status		1.05	0.99, 1.12	1.13	0.98, 1.29	1.07	0.98, 1.16	0.95	0.76, 1.19	0.95	0.76, 1.19	0.86	0.62, 1.20
Education		1.11**	1.03, 1.19	1.02	0.88, 1.17	1.03	0.93, 1.14	1.63* *	1.21, 2.18	1.63**	1.21, 2.18	1.16	0.84, 1.59
Language/ Immigration		0.89*	0.83, 0.94	0.85*	0.74, 0.98	0.85*	0.79, 0.92	1.00	0.75, 1.34	1.00	0.75, 1.33	1.01	0.24, 4.12
Residential Stability		1.08*	1.01, 1.14	1.02	0.91, 1.13	1.03	0.95, 1.11	1.17	0.96, 1.42	1.17	0.96, 1.42	1.33	0.99, 1.79
Neighbourhood characteristics													
Neighbourhood SES Index		0.91**	0.85, 0.98	0.91	0.78, 1.05	0.90*	0.83, 0.99	1.05	0.82, 1.35	1.05	0.82, 1.35	1.40	0.81, 2.43

\*p<0.05; \*\*p<0.01; ‡Province variable only pertains to Pan-Canadian Analysis # 1; †Province variable only pertains to Pan-Canadian Analysis # 2

Appendix 10

*Predictors of vulnerability on the Social Competence domain among kindergarten children with ASD after accounting for clustering by neighbourhoods*

Variable	Classification	Pan-Canadian Analysis # 1		Pan-Canadian Analysis # 2		Ontario		Alberta		British Columbia		Nova Scotia		Quebec	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics															
Age		0.99	0.85, 1.16	1.06	0.78, 1.43	0.87	0.68, 1.10	0.56*	0.35, 0.90	1.49	0.99, 2.25	0.79	0.44, 1.43	1.62	0.95, 2.75
Sex (Female)	Male	1.22*	1.05, 1.42	1.29	0.97, 1.73	1.17	0.96, 1.42	0.98	0.56, 1.72	1.26	0.84, 1.90	1.37	0.73, 2.57	1.77*	1.03, 3.06
EFSL status (No)	Yes	1.82*	1.48, 2.24	1.82*	1.12, 2.97	1.91*	1.43, 2.56	1.80	0.86, 3.79	2.03**	1.22, 3.39	1.50	0.27, 8.31	1.52	0.85, 2.75
Province (Ontario)‡	Manitoba	1.02	0.78, 1.33												
	Alberta	0.88	0.71, 1.09												
	British Columbia	0.99	0.84, 1.18												
	Nova Scotia	1.00	0.76, 1.32												
	Quebec	0.38*	0.31, 0.47												
Province (Ontario)†	British Columbia			-	-										
	Quebec			-	-										
	Prairies (Alberta,			-	-										

				Saskatchewan, Manitoba)										
				Atlantic provinces (Nova Scotia, Newfoundland)	0.77	0.58, 1.02								
Marital status	1.06	0.99, 1.13	1.08	0.93, 1.25	1.04	0.95, 1.14	1.26	0.99, 1.61	1.07	0.90, 1.30	0.95	0.67, 1.34	1.16	0.91, 1.49
Education	1.05	0.97, 1.14	1.04	0.90, 1.21	0.97	0.87, 1.09	1.06	0.80, 1.40	0.98	0.77, 1.25	1.28	0.90, 1.83	1.28*	1.02, 1.62
Language/ Immigration	1.05	0.98, 1.12	0.92	0.80, 1.07	1.02	0.94, 1.11	1.05	0.79, 1.41	1.07	0.91, 1.27	8.47	0.47, 151.5 6	1.17	0.87, 1.57
Residential Stability	1.03	0.97, 1.09	1.05	0.94, 1.18	0.98	0.90, 1.06	1.12	0.92, 1.37	1.22*	1.01, 1.46	1.14	0.83, 1.57	1.08	0.86, 1.35
Neighbourhood characteristics														
Neighbourhood SES Index	0.94	0.88, 1.01	1.01	0.86, 1.18	0.89*	0.81, 0.98	1.10	0.85, 1.43	0.91	0.73, 1.13	2.13 *	1.14, 4.01	1.05	0.83, 1.32

\*p<0.05; \*\*p<0.01; ‡Province variable only pertains to Pan-Canadian Analysis # 1; †Province variable only pertains to Pan-Canadian Analysis # 2

Appendix 11

*Predictors of vulnerability on the Emotional Maturity domain among kindergarten children with ASD after accounting for clustering by neighbourhoods*

Variable	Classification	Pan-Canadian Analysis # 1		Pan-Canadian Analysis # 2		Ontario		Alberta		British Columbia		Nova Scotia	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics													
Age		1.21*	1.03, 1.42	1.10	0.81, 1.50	1.16	0.91, 1.48	0.90	0.62, 1.31	1.78**	1.16, 2.77	1.14	0.62, 2.10
Sex (Female)	Male	1.33*	1.14, 1.55	1.55**	1.15, 2.07	1.26*	1.03, 1.53	0.93	0.53, 1.65	1.30	0.85, 1.97	1.62	0.86, 3.04
EFSL status (No)	Yes	1.72*	1.40, 2.12	1.73*	1.06, 2.82	1.95*	1.45, 2.62	1.09	0.53, 2.23	1.36	0.83, 2.23	3.59	0.41, 31.41
Province (Ontario)‡	Manitoba	0.98	0.75, 1.29										
	Alberta	0.84	0.68, 1.05										
	British Columbia	0.97	0.82, 1.15										
	Nova Scotia	0.78	0.59, 1.03										
	Quebec	0.53*	0.42, 0.66										
Province (Ontario)†	British Columbia			-	-								
	Quebec			-	-								
	Prairies (Alberta,			-	-								

	Saskatchewan, Manitoba)												
	Atlantic provinces (Nova Scotia, Newfoundland)			0.61**	0.46,								
Marital status		1.01	0.95, 1.08	1.11	0.96, 1.29	1.06	0.96, 1.16	1.11	0.87, 1.40	0.93	0.78, 1.13	0.83	0.59, 1.18
Education		1.07	0.98, 1.15	1.05	0.90, 1.22	1.00	0.89, 1.12	1.11	0.83, 1.48	1.07	0.83, 1.38	1.29	0.90, 1.84
Language/ Immigration		0.93*	0.87, 1.00	0.81**	0.70, 0.94	0.91*	0.84, 0.99	1.15	0.84, 1.58	0.99	0.84, 1.17	3.42	0.27, 43.55
Residential Stability		1.04	0.97, 1.11	1.04	0.92, 1.17	0.98	0.90, 1.07	1.23 *	1.01, 1.52	1.30*	1.06, 1.57	1.16	0.85, 1.60
Neighbourhood characteristics													
Neighbourhood SES Index		0.92*	0.85, 0.99	1.00	0.85, 1.18	0.91	0.83, 1.01	0.99	0.76, 1.30	0.73**	0.58, 0.91	1.79	0.96, 3.37

\*p<0.05; \*\*p<0.01; ‡Province variable only pertains to Pan-Canadian Analysis # 1; †Province variable only pertains to Pan-Canadian Analysis # 2

Appendix 12

*Predictors of vulnerability on the Language and Cognitive Development domain among kindergarten children with ASD after accounting for clustering by neighbourhoods*

Variable	Classification	Pan-Canadian Analysis # 1		Pan-Canadian Analysis # 2		Ontario		Manitoba		Alberta		British Columbia		Nova Scotia		Quebec	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>Individual characteristics</b>																	
Age		0.75*	0.64, 0.87	0.77	0.57, 1.04	0.59	0.47, 0.75	1.16	0.66, 2.05	0.50**	0.31, 0.80	1.49*	1.02, 2.20	0.83	0.46, 1.43	0.88	0.50, 1.57
Sex (Female)	Male	0.89	0.77, 1.04	0.99	0.73, 1.32	0.87	0.72, 1.06	1.00	0.51, 1.95	1.12	0.64, 1.95	0.82	0.55, 1.22	0.60	0.33, 2.57	1.16	0.66, 2.08
EFSL status (No)	Yes	1.86*	1.55, 2.23	1.62	1.06, 2.48	1.97*	1.54, 2.52	1.97	0.82, 4.70	2.72**	1.38, 5.37	1.62*	1.04, 2.48	2.47	0.53, 8.31	1.82	0.98, 3.35
<b>Province (Ontario)‡</b>																	
	Manitoba	1.48*	1.15, 1.91														
	Alberta	1.19	0.97, 1.47														
	British Columbia	1.11	0.94, 1.30														
	Nova Scotia	1.07	0.82, 1.41														
	Quebec	0.77	0.61, 0.98														
<b>Province (Ontario)†</b>																	
	British Columbia			-	-												
	Quebec			-	-												
	Prairies (Alberta, Saskatchewan, Manitoba)			-	-												
	Atlantic provinces			0.93	0.70, 1.23												

	(Nova Scotia, Newfoundland)															
Marital status	1.05	0.98, 1.12	1.04	0.90, 1.19	1.09 *	1.00, 1.19	1.10	0.85, 1.43	1.00	0.79, 1.25	1.08	0.91, 1.28	1.01	0.73, 1.34	0.89	0.68, 1.16
Education	1.18*	1.09, 1.28	1.16 *	1.01, 1.34	1.02	0.92, 1.14	1.42 **	1.10, 1.83	1.56**	1.17, 2.10	1.08 *	0.92, 1.26	1.29	0.93, 1.83	1.28	1.00, 1.63
Language/Immigration	1.00	0.94, 1.07	0.89	0.77, 1.03	1.02	0.94, 1.11	0.88	0.57, 1.37	1.06	0.80, 1.42	1.30	1.04, 1.63	0.54	0.14, 151.56	1.22	0.96, 1.55
Residential Stability	1.07*	1.00, 1.13	1.16 **	1.04, 1.30	1.04	0.96, 1.13	1.02	0.80, 1.29	1.11	0.90, 1.35	1.09	0.91, 1.30	1.20	0.90, 1.57	0.82	0.59, 1.14
Neighbourhood characteristics																
Neighbourhood SES Index	0.89* *	0.83, 0.96	0.97	0.83, 1.13	0.87 **	0.79, 0.95	0.74 *	0.55, 0.99	1.06	0.82, 1.38	0.87	0.70, 1.06	1.12	0.65, 4.01	1.02	0.79, 1.32

\*p<0.05; \*\*p<0.01; ‡Province variable only pertains to Pan-Canadian Analysis # 1; †Province variable only pertains to Pan-Canadian Analysis # 2

Appendix 13

*Predictors of vulnerability on the Communication Skills and General Knowledge domain among kindergarten children with ASD after accounting for clustering by neighbourhoods*

Variable	Classification	Pan-Canadian Analysis # 1		Pan-Canadian Analysis # 2		Ontario		Alberta		British Columbia		Nova Scotia		Quebec	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
<b>Individual characteristics</b>															
Age		0.90	0.77, 1.05	0.93	0.69, 1.26	0.74*	0.58, 0.94	0.62	0.38, 1.01	1.58*	1.05, 2.39	0.90	0.48, 1.68	1.14	0.67, 1.92
Sex (Female)	Male	1.05	0.90, 1.22	1.15	0.85, 1.54	1.03	0.84, 1.27	0.92	0.51, 1.67	1.04	0.68, 1.57	1.09	0.56, 2.10	1.04	0.61, 1.75
EFSL status (No)	Yes	2.64*	2.09, 3.32	2.84*	1.64, 4.91	3.29*	2.31, 4.67	6.23**	2.16, 18.36	2.16**	1.31, 3.56	1.21	0.22, 6.79	1.93*	1.08, 3.49
Province (Ontario)‡	Manitoba	1.21	0.91, 1.59												
	Alberta	0.94	0.76, 1.17												
	British Columbia	0.92	0.78, 1.09												
	Nova Scotia	1.04	0.78, 1.38												
	Quebec	0.36*	0.29, 0.46												
Province (Ontario)†	British Columbia			-	-										
	Quebec			-	-										
	Prairies (Alberta,			-	-										



			Saskatchewan, Manitoba)												
			Atlantic provinces (Nova Scotia, Newfoundland)	0.99	0.75, 1.32										
Marital status		1.05	0.98, 1.12	1.03	0.89, 1.19	1.08	0.98, 1.18	1.07	0.84, 1.36	0.99	0.83, 1.19	0.80	0.56, 1.15	1.11	0.86, 1.40
Education		1.10*	1.02, 1.20	0.97	0.84, 1.12	0.97	0.87, 1.09	1.46*	1.07, 1.99	1.25	0.97, 1.58	1.23	0.85, 1.76	1.26	1.00, 1.58
Language/ Immigration		1.10* *	1.02, 1.18	1.01	0.87, 1.17	1.15* *	1.06, 1.26	0.92	0.68, 1.24	0.99	0.84, 1.16	76.7 8*	1.28, 4600. 87	1.21	0.90, 1.63
Residential Stability		1.03	0.97, 1.10	1.14*	1.01, 1.28	0.95	0.87, 1.04	1.28*	1.04, 1.58	1.04	0.87, 1.25	1.73 **	1.21, 2.47	1.17	0.93, 1.46
Neighbourhood characteristics															
Neighbourhood SES Index		0.90* *	0.84, 0.97	1.00	0.85, 1.17	0.86* *	0.78, 0.94	1.20	0.91, 1.57	0.83	0.67, 1.02	2.25 *	1.14, 4.43	1.03	0.81, 1.30

\*p<0.05; \*\*p<0.01; ‡Province variable only pertains to Pan-Canadian Analysis # 1; †Province variable only pertains to Pan-Canadian Analysis # 2

## Appendix 14

### *Predictors of vulnerability on Physical Health and Well-Being domain among kindergarten children with ASD*

Variable	Classification	Manitoba		Saskatchewan		Newfoundland		Quebec	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics									
Age		0.89	0.40, 2.00	1.72	0.37, 7.99	1.62	0.82, 3.19	1.02	0.58, 1.78
Sex (Female)	Male	0.50	0.21, 1.17	0.44	0.11, 1.76	0.64	0.29, 1.43	0.49*	0.27, 0.91
EFSL status (No)	Yes	4.09	0.52, 32.21	2.2	0, 2.7	1.18	0.10, 14.34	0.71	0.39, 1.30
Marital status		1.15	0.77, 1.71	1.09	0.57, 2.07	1.19	0.77, 1.85	1.25	0.97, 1.61
Education		1.23	0.83, 1.83	1.29	0.60, 2.76	0.87	0.67, 1.14	1.11	0.88, 1.41
Language/ Immigration		1.43	0.73, 2.77	1.84	0.22, 15.70	0.33	0.02, 5.39	0.90	0.67, 1.21

Residential Stability	0.71*	0.51, 0.99	1.08	0.55, 2.13	0.99	0.70, 1.40	1.12	0.89, 1.41
Neighbourhood characteristics								
Neighbourhood SES Index	0.98	0.65, 1.50	1.00	0.43, 2.29	0.54*	0.33, 0.88	0.85	0.67, 1.09

\*p<0.05

## Appendix 15

### *Predictors of vulnerability on Social Competence domain among kindergarten children with ASD*

Variable	Classification	Manitoba		Saskatchewan		Newfoundland	
		OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics							
Age		0.89	0.40, 2.00	1.72	0.37, 7.99	1.30	0.57, 2.99
Sex (Female)	Male	0.50	0.21, 1.17	0.44	0.11, 1.76	0.52	0.22, 1.20
EFSL status (No)	Yes	4.09	0.52, 32.21	2.2	0, 2.9	1.54	0.13, 18.35
Marital status		1.15	0.77, 1.71	1.09	0.57, 2.07	1.24	0.72, 2.13
Education		1.23	0.83, 1.83	1.29	0.60, 2.76	0.89	0.64, 1.23
Language/Immigration		1.43	0.73, 2.77	1.84	0.22, 15.70	0.05*	0.00, 0.82
Residential Stability		0.71*	0.51, 0.99	1.08	0.55, 2.13	1.25	0.83, 1.89
Neighbourhood characteristics							
Neighbourhood SES Index		0.98	0.65, 1.50	1.00	0.43, 2.29	0.80	0.45, 1.44

\*p<0.05

Appendix 16

*Predictors of vulnerability on Emotional Maturity domain among kindergarten children with ASD*

Variable	Classification	Manitoba		Saskatchewan		Newfoundland		Quebec	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics									
Age		0.89	0.40, 2.00	0.93	0.27, 3.23	0.84	0.42, 1.68	1.66	0.98, 2.82
Sex (Female)	Male	0.50	0.21, 1.17	0.39	0.12, 1.25	0.39*	0.18, 0.85	0.43**	0.25, 0.72
EFSL status	Yes	4.09	0.52, 32.21	3.22	0.46, 22.73	1.62	0.08, 33.79	0.56	0.31, 1.03
	(No)								
Marital status		1.15	0.77, 1.71	1.48	0.94, 2.34	1.34	0.84, 2.14	0.95	0.74, 1.21
Education		1.23	0.83, 1.83	1.17	0.65, 2.09	0.93	0.71, 1.23	1.09	0.86, 1.37
Language/ Immigration		1.43	0.73, 2.77	1.31	0.47, 3.65	0.07	0.01, 1.09	0.93	0.70, 1.25
Residential Stability		0.71*	0.51, 0.99	0.65	0.38, 1.13	1.51*	1.06, 2.16	1.02	0.82, 1.27
Neighbourhood characteristics									
Neighbourhood SES Index		0.98	0.65, 1.50	1.83	0.90, 3.74	0.86	0.52, 1.39	0.95	0.75, 1.19

\*p<0.05; \*\*p<0.01

Appendix 17

*Predictors of vulnerability on Language and Cognitive Development domain among kindergarten children with ASD*

Variable	Classification	Saskatchewan		Newfoundland	
		OR	95% CI	OR	95% CI
Individual characteristics					
Age		1.31	0.43, 3.98	1.97	0.95, 4.08
Sex (Female)	Male	1.03	0.34, 3.17	0.89	0.37, 2.12
EFSL status	Yes	0.83	0.13, 5.27	0.61	0.05, 7.80
	(No)				
Marital status		1.05	0.70, 1.57	1.38	0.86, 2.21
Education		1.20	0.74, 1.95	1.11	0.84, 1.48
Language/Immigration		0.74	0.33, 1.66	0.02*	0.00, 0.89
Residential Stability		1.00	0.61, 1.65	1.64*	1.10, 2.42
Neighbourhood characteristics					
Neighbourhood SES Index		1.09	0.59, 2.03	1.03	0.61, 1.74

\*p<0.05

Appendix 18

*Predictors of vulnerability on Communication Skills and General Knowledge domain among kindergarten children with ASD*

Variable	Classification	Manitoba		Saskatchewan		Newfoundland	
		OR	95% CI	OR	95% CI	OR	95% CI
Individual characteristics							
Age		0.89	0.40, 2.00	4.73*	1.20, 18.67	1.28	0.63, 2.59
Sex (Female)	Male	0.50	0.21, 1.17	0.45	0.13, 1.54	0.42*	0.19, 0.91
EFSL status (No)	Yes	4.09	0.52, 32.21	0.53	0.05, 5.47	2.20	0.18, 26.50
Marital status		1.15	0.77, 1.71	1.27	0.75, 2.16	1.40	0.88, 2.23

Education	1.23	0.83, 1.83	1.47	0.81, 2.64	0.84	0.64, 1.10
Language/ Immigration	1.43	0.73, 2.77	2.01	0.41, 9.90	0.02*	0.00, 0.44
Residential Stability	0.71*	0.51, 0.99	1.09	0.61, 1.95	1.04	0.74, 1.48
Neighbourhood characteristics						
Neighbourhood SES Index	0.98	0.65, 1.50	0.94	0.48, 1.83	1.07	0.65, 1.74

\*p<0.05

## Appendix 19

*Predictors of proportion of kindergarten children with ASD with vulnerability on Physical Health and Well-Being domain in a neighbourhood*

Neighbourhood characteristics	Ontario		Alberta		British Columbia		Quebec	
	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI
Mean age	-2.53	-13.10, 8.04	-8.73	-22.21, 4.75	9.07	-6.42, 24.57	-3.96	-19.49, 11.57
% male	-0.09*	-0.18, -0.00	-0.18	-0.41, 0.05	-0.06	-0.22, 0.10	0.13	-0.04, 0.30
% EFSL	0.00	-0.12, 0.13	0.17	-0.12, 0.46	0.04	-0.18, 0.25	0.05	-0.13, 0.24
Mean % separated, divorced, or widowed	-1.00	-4.56, 2.56	0.83	-6.85, 8.51	-1.07	-7.26, 5.12	8.14	0.01, 16.28
Mean % above 15 years with no secondary diploma	4.96*	0.98, 8.94	8.72*	0.94, 16.49	3.22	-4.22, 10.67	2.77	-3.96, 9.50

Mean % not speaking either official language at home	-3.50*	-6.33, -0.68	0.56	-8.88, 10.00	-1.60	-7.18, 3.98	-4.34	-14.06, 5.39
Mean % of population who moved during the past 5 years	1.22	-2.23, 4.67	6.58	-0.80, 13.96	2.21	-4.30, 8.72	3.82	-3.44, 11.08
Number of kindergarten children with ASD in a neighbourhood	-1.63*	-2.91, -0.35	-1.61	-5.27, 2.06	0.13	-2.38, 2.64	-2.32	-6.06, 1.43
Neighbourhood SES Index	-1.51	-4.60, 1.58	4.99	-2.81, 12.78	-5.70	- , 11.87	-3.19	-10.11, 3.72

\*p<0.05

## Appendix 20

### *Predictors of proportion of kindergarten children with ASD with vulnerability on Social Competence domain in a neighbourhood*

Neighbourhood characteristics	Ontario		Alberta		British Columbia		Quebec	
	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI
Mean age	3.51	-6.64, 13.66	-8.61	-	10.79	-4.50, 26.09	15.28	-1.79, 32.35
% male	-0.04	-0.13, 0.05	0.02	-0.20, 0.24	0.04	-0.11, 0.20	0.13	-0.06, 0.32
% EFSL	0.13*	0.01, 0.25	0.15	-0.13, 0.42	0.20	-0.01, 0.41	-0.03	-0.24, 0.17
Mean % separated, divorced, or	-2.93	-6.37, 0.51	5.21	-2.14, 12.56	0.64	-5.48, 6.77	6.18	-2.76, 15.12

widowed								
Mean % above 15 years with no secondary diploma	1.69	-2.16, 5.54	2.48	-4.96, 9.92	2.62	-4.71, 9.94	2.42	-4.98, 9.81
Mean % not speaking either official language at home	0.19	-2.55, 2.92	1.03	-8.00, 10.06	0.37	-5.13, 5.86	4.48	-6.21, 15.17
Mean % of population who moved during the past 5 years	-0.38	-3.72, 2.96	3.21	-3.85, 10.26	7.19*	0.76, 13.61	2.00	-5.97, 9.98
Number of kindergarten children with ASD in a neighbourhood	-0.28	-1.52, 0.96	-0.45	-3.97, 3.07	-1.45	-3.92, 1.03	-0.96	-5.08, 3.16
Neighbourhood SES Index	-3.68*	-6.67, -0.69	3.88	-3.64, 11.39	1.20	-4.12, 8.05	-2.02	-9.62, 5.58

\*p<0.05

## Appendix 21

*Predictors of proportion of kindergarten children with ASD with vulnerability on Emotional Maturity domain in a neighbourhood*

Neighbourhood characteristics	Ontario		Alberta		British Columbia		Quebec	
	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI
Mean age	-2.53	-13.10, 8.04	-8.73	-22.21, 4.75	9.07	-6.42, 24.57	-3.96	-19.49, 11.57
% male	-0.09*	-0.18, -0.00	-0.18	-0.41, 0.05	-0.06	-0.22, 0.10	0.13	-0.04, 0.30

% EFSL	0.00	-0.12, 0.13	0.17	-0.12, 0.46	0.04	-0.18, 0.25	0.05	-0.13, 0.24
Mean % separated, divorced, or widowed	-1.00	-4.56, 2.56	0.83	-6.85, 8.51	-1.07	-7.26, 5.12	8.14	0.01, 16.28
Mean % above 15 years with no secondary diploma	4.96*	0.98, 8.94	8.72*	0.94, 16.49	3.22	-4.22, 10.67	2.77	-3.96, 9.50
Mean % not speaking either official language at home	-3.50*	-6.33, -0.68	0.56	-8.88, 10.00	-1.60	-7.18, 3.98	-4.34	-14.06, 5.39
Mean % of population who moved during the past 5 years	1.22	-2.23, 4.67	6.58	-0.80, 13.96	2.21	-4.30, 8.72	3.82	-3.44, 11.08
Number of kindergarten children with ASD in a neighbourhood	-1.63*	-2.91, -0.35	-1.61	-5.27, 2.06	0.13	-2.38, 2.64	-2.32	-6.06, 1.43
Neighbourhood SES Index	-1.51	-4.60, 1.58	4.99	-2.81, 12.78	-5.70	- , 11.87	-3.19	-10.11, 3.72
						, 0.48		

\*p<0.05



Appendix 22

*Predictors of proportion of kindergarten children with ASD with vulnerability on Language and Cognitive Development domain in a neighbourhood*

Neighbourhood characteristics	Ontario		Alberta		British Columbia		Quebec	
	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI
Mean age	-18.24**	-28.64, -7.85	-14.26*	-27.44, -1.08	13.06	-2.79, 28.91	-2.78	-18.47, 12.91
% male	-0.09*	-0.18, 0.00	-0.07	-0.30, 0.15	-0.03	-0.19, 0.13	0.10	-0.07, 0.27
% EFSL	0.12	-0.01, 0.24	0.25	-0.03, 0.53	0.03	-0.19, 0.25	0.11	-0.08, 0.30
Mean % separated, divorced, or widowed	-4.10*	-7.62, 0.57	3.82	-3.65, 11.30	1.33	-5.01, 7.67	0.96	-7.26, 9.17
Mean % above 15 years with no secondary diploma	2.26	-1.68, 6.20	11.30**	-3.74, 18.85	8.68*	1.06, 16.29	2.46	-4.34, 9.25
Mean % not speaking either official language at home	-0.11	-2.93, 2.70	0.72	-8.45, 9.90	5.05	-0.67, 10.76	-6.01	-15.83, 3.81
Mean % of population who moved during the past 5 years	1.18	-2.24, 4.59	4.75	-2.44, 11.93	5.17	-1.49, 11.83	2.91	-4.42, 10.23
Number of kindergarten children with ASD in a neighbourhood	-1.32*	-2.59, 0.05	-1.57	-5.15, 2.02	-1.67	-4.24, 0.90	0.53	-3.25, 4.32
Neighbourhood SES Index	-5.22**	-8.23, 2.16	4.41	-3.36, 12.18	-2.34	-8.66, 3.98	-0.60	-7.58, 6.39

\*p<0.05; \*\*p<0.01

Appendix 23

*Predictors of proportion of kindergarten children with ASD with vulnerability on Communication Skills and General Knowledge domain in a neighbourhood*

Neighbourhood characteristics	Ontario		Alberta		British Columbia		Quebec	
	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI	Unstandardized $\beta$	95% CI
Mean age	-1.54	-10.97, 7.89	-2.12	-14.70, 10.47	4.70	-10.22, 19.53	16.82*	0.26, 33.37
% male	0.01	-0.07, 0.09	-0.05	-0.26, 0.17	0.09	-0.07, 0.24	0.03	-0.16, 0.21
% EFSL	0.23***	0.12, 0.34	0.31*	0.04, 0.58	0.13	-0.07, 0.34	0.14	-0.06, 0.34
Mean % separated, divorced, or widowed	-1.12	-4.31, 2.08	0.35	-6.82, 7.51	-0.78	-6.70, 5.14	5.37	-3.31, 14.04
Mean % above 15 years with no secondary diploma	2.52	-1.05, 6.10	9.14*	1.89, 16.40	9.75**	2.63, 16.87	0.68	-6.50, 7.85
Mean % not speaking either official language at home	1.83	-0.71, 4.37	-4.03	-12.84, 4.78	0.66	-4.68, 6.00	3.28	-7.09, 13.64
Mean % of population who moved during the past 5 years	-2.12	-5.22, 0.98	7.67*	0.79, 14.56	1.63	-4.59, 7.86	2.29	-5.44, 10.02
Number of kindergarten	-1.92**	-3.07, -0.77	-1.22	-4.64, 2.20	-1.60	-4.00, 0.80	-2.68	-6.68, 1.31

children with ASD in a neighbourhood								
Neighbourhood	-4.61**	-7.38, -	5.03	-2.24,	0.03	-5.88,	-3.36	-10.73,
SES Index		1.83		12.30		5.94		4.01

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\*p<0.05; \*\*p<0.01; \*\*\*p<0.

**Chapter Four: Primary care provider and child characteristics associated with age of diagnosis of Autism Spectrum Disorder: A population-based cohort study**

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## Abstract

Early diagnosis of Autism Spectrum Disorder (ASD) can help children access early intervention services crucial for supporting their development. Examining provider and patient factors related to early diagnosis can inform ways in which pathways to early diagnosis can be improved. The objectives of this study are to determine among kindergarten children with ASD, (1) the association between characteristics of the primary care provider and age at first diagnosis of ASD, (2) the association between characteristics of these children and age at first diagnosis of ASD, and (3) the association between primary care provider's membership in primary care models and the length of time from age at first identification of delay in development to age at first diagnosis of ASD. We undertook a population-based cohort study using linked health and administrative data. Kindergarten-age children with a teacher-reported ASD diagnosis in the Early Development Instrument (EDI) database from January 1, 2015 to June 30, 2015 were included (n = 1522). The child's primary care provider was identified using outpatient physician billings data and child characteristics were determined at the time of the EDI completion. Age of the first health record of an ASD diagnosis was the main outcome measure. Cox proportional hazard models were used to test associations. Median age at ASD diagnosis was 1263 days (Q<sub>1</sub>-Q<sub>3</sub>: 983-1620). There were no differences in age at diagnosis by primary care provider's sex, membership in primary care models, and years in practice. There were also no differences in age at diagnosis by child's sex, location of residence, maternal age and immigration status. Children with primary care providers with foreign medical training had older age at ASD diagnosis than children

with primary care providers with domestic medical training (foreign training median (Q<sub>1</sub>-Q<sub>3</sub>): 1289 days (1020-1630); domestic training median (Q<sub>1</sub>-Q<sub>3</sub>): 1238 days (959-1596); adjusted HR 1.2 (95% CI 1.2, 1.4),  $p < 0.01$ ). After children received their first identification of delay in development, children with paediatricians as primary care providers had longer time to diagnosis than children with primary care providers in primary care models (paediatrician median (Q<sub>1</sub>-Q<sub>3</sub>): 479 days (230-832); provider in primary care model median (Q<sub>1</sub>-Q<sub>3</sub>): 352 days (198-873); adjusted HR 0.68 (95% CI 0.54, 0.86),  $p < 0.05$ ). These findings can be used to inform primary care provider ASD training, specifically focusing on providers with foreign training and paediatricians, as well as targeted primary care interventions to shorten time to diagnosis.

Key words: ASD, developmental disabilities, diagnosis, kindergarten, primary care, paediatricians

## **1. Introduction**

Autism Spectrum Disorder (ASD) can reliably be diagnosed by the age of 2 years, yet the median age of ASD diagnosis remains over the age of 4 years (Christensen et al., 2016; Kleinman et al 2008). In 2014, a U.S. surveillance study found that 58.1% of children with ASD received their first diagnosis after the age of 3 years and the median age of diagnosis among these children was 4.3 years (Baio et al., 2018). Early diagnosis of ASD is important as it can lead to earlier intervention, which has been associated with better developmental outcomes compared to children who are treated later (Gibbs et al., 2019). While access to appropriate developmental services and the quality of clinical evaluations can influence when a diagnosis of ASD occurs, health care provider and child demographic and clinical characteristics may also be important for early recognition of developmental concerns, referral for appropriate assessments, and timely diagnoses (Kalkbrenner et al., 2011; Mandell, Novak, & Zubritsky, 2005; Rutherford et al., 2018; Thomas et al., 2012). Identifying child and provider factors associated with the age of identification of delay in development and diagnosis of ASD is important for targeted improvements in pathways to early diagnosis.

In Canada, the majority of primary care is provided to children through family physicians and primary care paediatricians. While in Canada both physicians and psychologists may make a diagnosis of ASD, (Brian, Zwaigenbaum, & Ip, 2019) most children identified with concerns about their development in social and communication domains will be referred to, assessed, and diagnosed by consultant general paediatricians and developmental paediatricians (Penner, Anagnostou, & Ungar, 2018, Hameed, Shariff,

Perry, & Dickinson, 2013). Despite there being several published guidelines and diagnostic tools for ASD diagnosis and management, no single tool is used to ascertain if a child meets the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM – 5) diagnostic criteria for ASD (Penner et al., 2018; American Psychiatric Association, 2013; Dua, 2003; The Miriam Foundation, 2008). The current ‘gold standard’ approach to ASD diagnosis and recommended in most ASD diagnosis guidelines is a multidisciplinary team (MDT) based approach (Falkmer, Anderson, Falkmer, & Horlin, 2013; Brian et al., 2019). This may be led by a primary care provider, paediatric consultant, or clinical psychologist trained to diagnose ASD (Brian et al., 2019). Members of the MDT team work collaboratively to share information though work independently to reach a diagnostic decision (Brian et al., 2019). Family physicians, primary care paediatricians, parents or other caregivers typically first identify concerns about children who are suspected to have ASD based on a wide range and severity of symptoms related to language, communication and social skills development (Brian et al., 2019). To improve early detection of developmental problems, the Canadian Paediatric Society (CPS) recommends developmental surveillance at each scheduled health visit (Zwaigenbaum, Brian, & Ip, 2019a). This involves integrating information gathered from parental concerns, clinical observations, developmental screening, and sometimes from standardized tools to inform clinical impressions and decision-making. When developmental concerns arise through surveillance, children should receive further diagnostic assessment either from a specialized team or paediatricians providing consulting care who are trained in the diagnosis and assessment of ASD. The CPS



recommends a flexible diagnosis pathway according to the complexity of the symptoms, health care provider's personal experience and clinical judgement, as well as the availability of local health resources. Despite guidelines for diagnostic pathways, wide variation in time to diagnosis exists among regions (Coo et al., 2012). This variation suggests there may be opportunities to improve timeliness of diagnosis.

Several characteristics of physician practice models may influence the age of ASD diagnosis. In Ontario, primary care physicians can work in a variety of primary care models, characterized by different requirements including patient enrolment, group-based care, and remuneration methods consisting of different combinations of fee-for-service, capitation, pay-for-performance, and salary. These models of care have been well described elsewhere (McLeod, Buckley, & Sweetman, 2016). Models that encompass an interdisciplinary team based approach (e.g. psychology and social work) have potential to be beneficial in facilitating early ASD diagnoses given their infrastructure for access to more specialized primary care and consultant services, especially compared to walk-in-clinic or fee-for-service models where physicians practice solo. In Ontario, Manitoba, and Quebec, paediatricians provide a substantial proportion of primary care to young children (Canadian Paediatric Society, 2004). Primary care paediatricians do not practice in primary care models and are typically remunerated through traditional fee-for-service (Glazier, Zagorski, & Rayner, 2012). Primary care physicians' transition from traditional fee-for-service to membership in primary care model has been associated with decrease in continuity and coordination of specialized care (Singh, Dahrouge, & Green, 2019). This may be particularly relevant in the context of ASD diagnosis as referrals to multiple

health care providers may be needed to diagnose this disorder.

Physician training location may also influence ASD diagnosis. Canadian medical graduates and international medical graduates differ in the rates of referrals for some medical tests (colonoscopy), provision of preventative and maternity care, and prescription of antibiotics and other medications (Neiterman, Bourgeault, & Covell, 2017). Several hypotheses have been proposed to explain these differences, including differences in physician knowledge – international medical graduates usually score lower than Canadian and US graduates on licensing exams (Ben-David et al., 1999). However, there is also evidence indicating that differences in primary care practices between Canadian medical graduates and international medical graduates are not accounted by differences in knowledge. Cadieux et al. (2007) found that after adjusting for physician knowledge, international medical graduates were more likely to prescribe antibiotics inappropriately compared to Canadian medical graduates. They have noted differences in training environments may explain these prescribing practices – it is possible that international medical graduates prescribe antibiotics according to cultural expectations or the probability of bacterial infection in country of their medical training. Given these differences, it is possible that primary care providers with domestic medical training may approach ASD diagnosis differently compared to those with foreign medical training.

The age of ASD diagnosis may also depend on individual, child characteristics. Having milder symptoms and living in rural areas have been associated with later age at ASD diagnosis (Mandell et al., 2005). Children with severe symptoms may have earlier diagnosis than children with milder symptoms as physicians and parents may find severe

symptoms easier to recognize because of their functional impact, which can prompt further evaluation (Mandell et al., 2005). These include symptoms such as severe language deficits, whereas symptoms such as oversensitivity to pain may not be readily considered as a developmental issue (Mandell et al., 2005). In contrast, Zwaigenbaum et al. (2019b) found higher levels of restricted repetitive behaviour symptoms were associated with later diagnosis. However, they indicated this finding may be attributed to reduced restricted repetitive behaviour symptom reporting among the youngest participants in their study sample (Zwaigenbaum et al., 2019b). There are inconsistent findings regarding sex differences in the timing of ASD diagnosis (Shattuck et al., 2009; Fountain, King, & Bearman, 2011; Fujiwara, Okuyama, & Funahashi, 2011). There are also mixed findings regarding the association between socioeconomic status of children's area of residence and their age at ASD diagnosis (Daniels & Mandell, 2014; Thomas et al., 2012).

Understanding the relationship between characteristics of children with ASD and their primary care providers with age at diagnosis can help identify opportunities for improving how we train providers and enhance the health system structure for developmental assessments. Examining this relationship among kindergarten aged children is particularly relevant considering the median age of diagnosis remains over 4 years. The objectives of this study are to determine, among kindergarten children with ASD, (1) the association between characteristics of the primary care provider and age at first diagnosis of ASD, (2) the association between characteristics of these children and age at first diagnosis of ASD, and (3) the association between primary care provider's

membership in primary care models and the length of time from age at first identification of delay in development to age at first diagnosis of ASD.

## **2. Methods**

### ***2.1 Study Design and Setting***

We conducted a population-based cohort study of kindergarten children with ASD in Ontario, Canada using health and administrative datasets linked at ICES, a not-for-profit research institute whose legal status under Ontario's health information privacy law allows it to collect and analyze health data without individual consent. Ethics approval was obtained from The Hamilton Integrated Research Ethics Board and The Hospital of Sick Children in Toronto, Ontario.

### ***2.2 Data Sources***

A number of databases available at ICES were used. They were linked using unique encoded identifiers and analyzed at ICES.

The Early Development Instrument (EDI) is completed by kindergarten teachers of children aged 5 to 6 years in second half of the kindergarten year (Janus et al., 2007). The EDI contains 103 items covering five broad domains of readiness to learn at school and thus reflects the outcomes of early child development (Janus & Offord, 2007). These domains are physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication and general knowledge. Scores below a baseline 10th percent cut-off on any of the 5 domains indicate vulnerability, and vulnerability on one or more domains indicates overall vulnerability (Janus & Offord,

2007). Since 2010, the EDI also includes information on children's medical diagnoses, including a teacher-reported ASD diagnosis. Teachers' report had to be based on the information from the child's parent/legal guardian or school support services (<https://edi.offordcentre.com/teachers/>). The psychometric properties and validity of the EDI have been reported elsewhere (Janus & Offord, 2007; Janus et al., 2007; Guhn et al., 2016).

The Ontario Health Insurance Plan Claims database (OHIP) identifies outpatient physician billing claims for physician services in Ontario. The OHIP database was used to determine developmental delay and ASD related outpatient visits as well as a child's primary care provider. The National Ambulatory Care Reporting System (NACRS) and Canadian Institute for Health Information Discharge Abstract Database (DAD) were used to determine developmental delay and ASD related emergency department visits and hospitalizations, respectively. The Client Agency Program Enrolment (CAPE) database was used to identify child's primary care provider's membership in a primary care model. The ICES Physician Database (IPDB) identified primary care provider's demographic characteristics.

The Registered Person's Database (RPDB) includes demographic information for all residents eligible for provincially insured health care. The RPDB was used to examine the child's sex and the Statistics Canada Postal Code Conversion File (PCCF) was linked with children's postal codes in the RPDB to determine rural and urban residence. The 2008 Rurality Index of Ontario (RIO) from the RPDB was used to determine whether children lived in urban (RIO <39) or rural (RIO  $\geq$ 40) areas (Kralj, 2008). Teen

motherhood at the time of first birth was determined with the MOMBABY, an ICES-derived database that links the inpatient hospital admission records of delivering mothers and their newborns. The Immigrants, Refugees and Citizenship Canada's Permanent Resident Database (IRCC) includes demographic information on all immigrants with permanent residency status who arrived in Ontario from 1985 to 2017. This database was probabilistically and deterministically linked to the RPDB, with validation of linkage previously described (Chiu et al., 2016). The IRCC was used to examine maternal immigration status. The Ontario Marginalization Index (ONMARG) database includes socioeconomic information for dissemination areas identified using postal codes based on the Census (Matheson & Public Health Ontario, 2017). There are four dimensions in this index: residential stability, material deprivation, dependency, and ethnic concentration. The ONMARG is a validated census- and geographically based index that examines differences in marginalization between different geographic areas and examines inequalities in social well-being and health – it applies to areas and not to individual people (Matheson & Public Health Ontario, 2017). To examine socioeconomic status of the child's area of residence, children's postal codes were linked with the PCCF to derive material deprivation quintile data at the dissemination area level from the 2011 ONMARG. A dissemination area is a small and relatively stable geographic area that consists of one or more adjacent dissemination blocks with an average population of 400 to 700 persons – dissemination areas cover all the territory of Canada.

### ***2.3 Study Population and Period***

There were 1872 children with ASD diagnosis reported by teachers in the EDI database between January 1, 2015 and June 30, 2015. These children were deterministically linked with the ICES databases using sex, date of birth, and postal code (positive predictive value: 89%) (unpublished data). Children who were not residents of Ontario on the day of EDI completion, whose health card number was invalid or missing, information on age or sex were missing, age was not between 1825 and 2190 days (5 and 6 years), and those with data linkage warning issues in MOMBABY were excluded from this study, with 1522 children included in the study (Figure 1).

### ***2.4 Study Measures***

#### ***Exposures***

The primary care provider most responsible for the child's primary care in the first 3 years was identified using OHIP billing records. A child's most responsible primary care provider was the one with the greatest number of visits using primary care billing codes in the first three years of life as identified using OHIP billing records (see Appendix 1 for primary care visit codes). For children who obtained OHIP eligibility after age 3 years, their most responsible primary care provider was the one with the greatest number of visits in the first year after obtaining provincial health insurance. If there was a tie between primary care providers in terms of the total number of visits, the physician who saw the child most recently was identified as the most responsible primary care provider. Once primary care providers were assigned, the CAPE database was used

to identify children rostered in primary care models. For non-rostered children, the primary care provider included physicians who did not work under a primary care model, as well as paediatricians. The IPDB database was used to identify other primary care provider characteristics as follows: primary care physician's sex, years in practice after medical school graduation, and location of medical training (domestic / foreign).

The characteristics of children were considered on the date of EDI completion as follows: sex, location of residence (urban / rural), teen motherhood at the time of first birth (yes / no), mother's immigration status (immigrant / refugee / non-immigrant).

### ***Outcomes***

Age at first ASD diagnosis was calculated by identifying the first time when a child received the diagnosis for this disorder as indicated by relevant codes in the OHIP, NACRS, or DAD databases (see Appendix 2 for ASD diagnosis codes). Age of ASD diagnosis was classified as missing for children who had ASD diagnosis in the EDI but not in the OHIP, NACRS, or DAD databases.

Age at first identification of delay in development was calculated by identifying the first time when a child received the delay in development diagnosis as indicated by relevant codes in the OHIP, NACRS, or DAD databases (see Appendix 3 for delay in development codes).

### ***Covariates***

A number of clinically and biologically plausible covariates, potentially related to the timing of diagnosis of ASD were considered. Children's vulnerability on the EDI



domains (yes / no) was used to examine severity of developmental disability in a child. There is evidence indicating children with ASD show poorer developmental outcomes as measured by the EDI in all five areas of development – indicating vulnerability on the EDI is an appropriate proxy measure for severity of developmental disability for children with this diagnosis (Janus et al., 2018). Since children with ASD with milder symptoms (indicated by lack of vulnerability on any EDI domain) may be more difficult to detect and take longer to diagnose compared to those with more severe ASD symptoms (showing overall vulnerability), the analyses were stratified by vulnerability on the EDI. Presence of complex chronic conditions and technological dependence was measured based on previously published and validated methodology using DAD and NACRS (Feudtner et al., 2014).

### **3. Analysis**

Descriptive statistics summarized the independent and outcome variables, and covariates. Age at first ASD diagnosis, as well as duration of time between age at first identification of delay in development and age at first ASD diagnosis, were examined by primary care provider and child characteristics. Descriptive statistics for age at ASD diagnosis were also stratified by severity of developmental disability – separate analyses were completed for children who were and were not vulnerable overall on the EDI.

Cox proportional hazards (PH) models (using child's calendar age in days as the underlying timescale) were used to estimate the hazard ratios and 95% CIs of ASD diagnosis in children according to exposure variables. Observations were censored if a

child age of diagnosis was missing. Univariate Cox PH models were used to determine the unadjusted association between each primary care provider (primary care physician's sex, years in practice, location of medical training, membership in primary care model) and child (sex, location of residence, teen motherhood, mother's immigration status) characteristic, as well as covariates specified a priori (severity of developmental disability, presence of complex chronic conditions and technological dependence), and age at first ASD diagnosis. A multivariable Cox PH model was used to determine the association between each primary care provider and child characteristic and age at first ASD diagnosis, adjusted for all primary care provider and child characteristics as well as covariates. Similar analyses were conducted by stratifying the sample by severity of developmental disability – one group included children who were not vulnerable on any EDI domain and the second group included children who were vulnerable on one or more domains. The only covariate adjusted for in these stratified analyses was the presence of complex chronic conditions and technological dependence.

To examine the association between primary care provider's membership in primary care models and the length of time from age at first identification of delay in development to age at first diagnosis of ASD, we used Kaplan-Meier analysis and Cox PH models. Kaplan-Meier analysis was used to examine differences in children's probability of receiving ASD diagnosis after the age at first delay identification according to primary care provider's membership in care models. Observations were censored if length of time between age of delay identification to age of ASD diagnosis was missing in the ICES databases (n=172), or if ASD diagnosis occurred before delay identification

(n=190). The Kaplan-Meier analyses were conducted in a stratified manner – one group included children who received ASD diagnosis after delay identification and those who received diagnosis before delay identification; the second group only included children who received ASD diagnosis after receiving delay identification.

Another set of analyses was conducted to account for covariates. Cox PH models (using length of time between child's calendar age at first delay identification to age at first ASD diagnosis in days as the underlying timescale) were used to estimate the hazard ratios and 95% CIs of ASD diagnosis in children according to primary care provider's membership in care models. Observations were censored in the same manner as the Kaplan-Meier analyses. Univariate Cox PH models were used to determine the unadjusted association between primary care provider's membership in primary care models, other primary care provider (primary care physician's sex, years in practice, location of medical training) and child characteristics (sex, location of residence, teen motherhood, mother's immigration status), as well as covariates specified a priori (severity of developmental disability, presence of complex chronic conditions and technological dependence), and age at first ASD diagnosis. A multivariable Cox PH model was used to determine the association between primary care provider's membership in primary care models and age at first ASD diagnosis, adjusted for other primary care provider and child characteristics as well as covariates. These Cox PH models were stratified in the same manner as the Kaplan-Meier analyses. For all Cox PH models to address all study objectives, children were excluded from analyses if they had missing values for variables in the model. The exact sample sizes for each of the analyses

are indicated in the results tables.

#### **4. Results**

Demographic characteristics of the children with ASD and their primary care provider are summarized in Table 1. Overall, 1240 (81.5%) of children in this study were male. The percentages of children living in the five material deprivation quintiles varied little: from 18.9% in the second least deprived to a modest high of 21.6% in the most deprived. 1357 (89.2%) of children were vulnerable overall, with the domain level vulnerability ranging from 41.5% in language and cognitive development to 71.4% in emotional maturity. Only 124 (8.2%) children in the sample had comorbidities or technological dependence.

Overall, 928 (62.7%) primary care physicians were male. The majority of primary care providers practiced for 21 or more years (76.1%) and had domestic medical training (59.7%). Of the cohort, 63.4% had primary care providers in care models, 5.8% had primary care providers not in care models, 28.1% received primary care from paediatricians, and 2.7% had no primary care provider.

##### ***4.1 Age at diagnosis of ASD***

Age at first ASD diagnosis was available for 1329 children. The median age of ASD diagnosis was 1263 days (Q<sub>1</sub>-Q<sub>3</sub>: 983-1620). Appendix 4 shows age of ASD diagnosis according to child and primary care provider characteristics. The median age of ASD diagnosis for children who were and were not vulnerable overall were 1272 days (Q<sub>1</sub>-Q<sub>3</sub>: 983-1625) and 1219 days (Q<sub>1</sub>-Q<sub>3</sub>: 975-1567), respectively, and these ages did not

differ statistically. Table 2 shows age of ASD diagnosis for these two sub-samples according to child and primary care provider characteristics. There were no significant differences in age of diagnosis between males and females in either group.

Proportional hazards assumption of Cox PH models was checked using proportionality tests and Schoenfeld residuals. Maternal age at first delivery and immigration status was not available for 168 children (representing 11% of sample). Since these 168 children and those with missing data on remaining independent variables were excluded from the adjusted analyses, the sample sizes in the adjusted and unadjusted analyses were not considered comparable. Demographic and primary care provider characteristics of children with missing data for maternal age and immigration status are shown in Appendix 5.

Results of multivariable Cox PH models examining the adjusted associations between primary care provider and child characteristics with age at first ASD diagnosis show different results for the whole sample and stratified analyses according to severity of developmental disability. Among children who were vulnerable, the univariate Cox PH models showed that providers with domestic training had 1.17-fold higher risk of ASD diagnosis<sup>2</sup> (95% CI 1.04, 1.31) compared to providers with foreign training (Table 3). Children without a primary care provider had 0.57-fold lower risk of ASD diagnosis (95% CI 0.38, 0.86) compared to children with primary care provider in care models. The

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<sup>2</sup> Higher risk of ASD diagnosis indicates increased likelihood of ASD diagnosis – in other words, children with specific exposure variables associated with higher risk of ASD diagnosis have shorter time to diagnosis and are diagnosed at a younger age.

adjusted risk of ASD diagnosis for providers with foreign training was the same in the multivariable Cox PH model (Hazard Ratio: 1.17, 95% CI 1.03, 1.33).

Among children who were not vulnerable, the univariate Cox PH models showed children without a primary care provider had 0.31-fold lower risk of ASD diagnosis (95% CI 0.11, 0.88) (Table 4). Children who lived in rural areas had 2.79-fold higher risk of ASD diagnosis (95% CI 1.12, 6.92) compared to children who lived in urban areas. There were no significant associations between primary care provider and child characteristics with age at ASD diagnosis in the multivariable Cox PH model. Appendix 6 shows Cox PH models for whole sample.

#### ***4.2 Time between identification of delay in development and ASD diagnosis***

The length of time between age of first identification of delay in development and age at first ASD diagnosis was available for 1157 children. Overall, 967 (63.5%) children received their ASD diagnosis after delay identification. The median length of time between delay identification and ASD diagnosis among these children was 388 days (Q<sub>1</sub>-Q<sub>3</sub>: 154-744). Table 5 shows the length of time between delay identification and ASD diagnosis according to child and primary care provider characteristics. The median length was 479 days (Q<sub>1</sub>-Q<sub>3</sub>: 230-832) if primary care provider was a paediatrician; 354 days (Q<sub>1</sub>-Q<sub>3</sub>: 146-686) if the primary care provider was in care model; 352 days (Q<sub>1</sub>-Q<sub>3</sub>: 198-873) if there was no primary care provider; and 223 days (Q<sub>1</sub>-Q<sub>3</sub>: 115-677) if primary care provider was not in care model.

The Kaplan-Meier analyses show no significant differences in probability of

receiving ASD diagnosis after the age at first delay identification according to primary care provider's membership in care models either for the whole sample, (Figure 2;  $p=0.07$ ), or children who received ASD diagnosis after delay identification (Figure 3;  $p=0.07$ ).

Among the whole sample and children who received ASD diagnosis after delay identification, the univariate Cox PH models showed that providers with domestic training had 1.20-fold higher risk of ASD diagnosis (95% CI 1.05, 1.37) after delay identification compared to providers with foreign training (Tables 6 and 7). Children with a paediatrician as primary care provider had 0.84-fold lower risk of ASD diagnosis (95% CI 0.73, 0.97) compared to children with primary care provider in care model (Tables 6 and 7). When children who received ASD diagnosis after delay identification were examined separately, the multivariable Cox PH model showed children with a paediatrician as primary care provider had 0.68-fold lower risk of ASD diagnosis (95% CI 0.54, 0.86) (Table 7).

## **5. Discussion**

In this cohort study of kindergarten children with ASD, the median age at first ASD diagnosis was 1263 days (3.5 years). We found primary care provider characteristics associated with age at ASD diagnosis varied according to severity of developmental disability observed by kindergarten teachers. Children who were vulnerable on the EDI were diagnosed with ASD earlier if their provider was domestically trained than children with foreign-trained providers, whereas this was not observed among children who were not vulnerable (i.e., had less severe symptoms of ASD). None of the child characteristics

examined in this study were associated with age of diagnosis. After children were identified with delay in development, children with primary care provider in care models were diagnosed with ASD earlier compared to children with paediatrician as primary care provider.

A diagnosis of ASD is often delayed with respect to first identification of developmental concern, which leads to missed opportunities to provide early interventions among children during a critical period of their development (Daniels & Mandell, 2014; National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 2018). Our study showed that the median age at which children received their first ASD diagnosis was six months younger than the commonly reported median age of diagnosis found in the literature (over age of 4 years); other studies showed a significant proportion of children are not diagnosed until school age (Shattuck et al., 2009). Factors such as variation in symptom presentation across cases and symptoms that change or appear infrequently may contribute to the consistency of reports of the age of diagnosis at 4 years (Kleinman et al., 2008; Le Couteur, Haden, Hammal, & McConachie, 2008). While these factors may also be relevant in the Ontario setting, the younger age of ASD diagnosis observed in this study highlights the importance of examining factors associated with age of diagnosis in a local context.

The age of diagnosis was not statistically significantly different between children who were and were not vulnerable. This contrasts with existing evidence where severity of condition has been associated with earlier age at identification of ASD (Sheldrick, Maye, & Carter, 2017). This may be attributed to the measure of severity we used in this



study. While the EDI reliably measures children's developmental status (Janus et al., 2007), and children with ASD are more likely to be observed as vulnerable than typically developing children (Janus et al., 2018), it was not designed to measure specific symptoms associated with ASD such as repetitive behaviours (Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013). Furthermore, the EDI was not validated against the DSM – 5 diagnostic criteria for measuring the severity of ASD (American Psychiatric Association, 2013). Nonetheless, broad developmental data as provided by the EDI are valuable in examining severity of developmental disability among children with ASD as they are available at the population level in most provinces and territories across Canada, thus including relatively large samples of young children with ASD (Siddiqua, Duku, Georgiades, Mesterman, & Janus, 2019).

Child, family, and community level characteristics that are associated with age of diagnosis of ASD are being investigated with increasing frequency (Daniels & Mandell, 2014). While there have been a few studies in this area in Canada, none examined the relationship between primary care provider characteristics and age of diagnosis of ASD (Ouellette-Kuntz et al., 2009; Burstyn, Sithole, & Zwaigenbaum, 2010; Coo et al., 2012; Frenette et al., 2013; Zwaigenbaum et al., 2019b). Our study shows that the primary care provider characteristics associated with age at first ASD diagnosis vary according to severity of developmental disability. We found that among children who demonstrated overall vulnerability, those who had primary care providers with domestic training were diagnosed earlier compared to those who had providers with foreign training. This finding is not to reflect negatively on foreign training per se – rather, this may be reflective of the

differential exposure to education about ASD, especially at early ages, that these clinicians received in different settings. If domestic primary care providers received greater levels of training relevant to ASD, they may be better positioned to diagnose children with this disorder earlier. This may be particularly relevant if the prevalence of children with ASD in countries where foreign medical graduates received their training is much lower – thus, early identification of this disorder may not have been emphasized in their training. Without specific knowledge of ASD, clinicians may not further explore the possibility of a diagnosis of this disorder (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Family physicians identified lack of adequate training on child development and screening methods as a major barrier for routine screening for ASD (Fenikilé, Ellerbeck, Filippi, & Daley, 2015). Differences in awareness of and diagnostic practices for ASD have been observed among health care providers based on their educational background. Family physicians who received some training specific to ASD had significantly higher compliance in terms of their awareness of clinical features of ASD observed in children in relation to the DSM – 5 criteria, when compared to family physicians without such training (Altay, 2019). Additionally, family physicians who were exposed to ASD-specific training referred more patients with a presumed diagnosis of ASD in a 6 month-window than family physicians who were not (Altay, 2019). It is also possible that given the uncertainty associated with making an early diagnosis, some countries where foreign medical graduates received their training may use a cautionary approach to diagnosis. One important factor we were not able to examine in our study was the number of years providers with foreign training practiced medicine in Canada, as this can serve as proxy

for the extent of their domestic training and familiarity with local diagnostic practices, which can have important implications for time to diagnosis.

In contrast to much of previous research (Daniels & Mandell, 2014; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012; Mandell et al., 2005; Zwaigenbaum et al., 2019b), we found no association between any of the child characteristics considered in this study with age at diagnosis of ASD. This highlights the importance of using context specific evidence when identifying factors to address to lower age of diagnosis of ASD. For example, evidence from the U.S. showed that children living in higher income areas compared to children in lower income were younger at the time of diagnosis and experienced more professional evaluations (Thomas et al., 2012). We found no association between the child's neighbourhood material deprivation index and age at diagnosis, similarly to another Canadian study that found no association between neighbourhood income and age of diagnosis of ASD (Coo et al., 2012).

The importance of early intervention is consistently emphasized by health care providers, however, there is typically a significant time lag from the age at which parental concerns are first identified to the age of first ASD diagnosis (Wiggins, Baio, & Rice, 2006). In contrast to existing evidence, we found that it took more time for children to receive the ASD diagnosis after the identification of delay in development for children who had a paediatrician as their primary care provider than for children who had a primary care provider in a care model. While there is no published evidence, it is possible that paediatricians, who complete a longer period of specialized residency in Canada lasting four years, may feel more compelled to monitor the child's development before

referring them to more specialists for diagnosis. In contrast, family physicians, who complete a shorter general residency lasting two years, may feel less prepared to make any diagnosis and more likely to refer to specialists. In our study, we did not examine the proportion of providers who were members in primary care models with an interdisciplinary team based approach to care, which can further contextualize the time difference between delay identification and ASD diagnosis. Wiggins et al. (2006) found that although most parents became concerned regarding their child's development between 12 and 23 months of age, these children did not receive their diagnosis until 36 to 70 months of age. There is evidence indicating that the average age at which first documented evaluation occurs by a qualified professional is at 48 months, whereas the average age at which the first documented ASD diagnosis occurs is at 61 months with a 13 month long wait period (Wiggins et al., 2006). In this study, the median wait period from identification of development delay to ASD diagnosis was 388 days (12.9 months, just over 1 year) among 64% of children (those who received ASD diagnosis after receiving identification of delay in development). In the U.S., it has been found that paediatricians are more likely to refer children to specialists than to conduct developmental tests themselves (Mandell et al., 2005). Taken together with our findings, this highlights the importance of further examining the diagnostic and referral practices implemented by paediatricians and primary care providers in care models in a Canadian context in order to reduce age of ASD diagnosis of children who seek primary care from them.

There are a number of limitations to this study. It was not possible to identify age

of diagnosis for 193 (12.68%) children who have been identified with an ASD diagnosis in the EDI database. This may be attributed to an ASD diagnosis made by professionals who are not physicians, such as psychologists, and thus not captured in the billing records in the OHIP, NACRS, and DAD databases. There has been no validation of the combination of codes from the OHIP, NACRS, and DAD databases used to identify delay in development using administrative data, thus misclassification of data for this outcome has not been assessed. For children who obtained OHIP eligibility after age 3 years, their age at first identification of delay in development and age at first diagnosis of ASD may be biased upwards given their later access to health care services. Based on the current diagnostic practices recommended in Canada, we hypothesized children would be first identified with developmental delay and subsequently receive their ASD diagnosis. However, 190 (12.5%) children in our study received their ASD diagnosis before delay in development was identified. There may be residual confounding from unknown or unmeasured covariates, which can bias the associations between characteristics of primary care providers and children with ASD with age at diagnosis of this disorder. For example, we did not have data on birth order and family heritability, both of which have been associated with an earlier diagnosis of ASD (Chaste & Leboyer, 2012; Risch et al., 2014). There are also some inherent limitations from the use of administrative datasets. These include potential coding errors and the imperfect and transient nature of encoded identifiers that are used for data linkage. In our study, while 1872 children had ASD diagnosis in the EDI database, 345 of them were excluded due to invalid encoded health identification numbers (Figure 1).

This study also had several key strengths. It included a large sample size (n=1522), which is among one of the largest samples from a single Canadian province to examine factors associated with age of diagnosis of children with ASD. While primary care models are an integral component of health care delivery in Ontario, this is the first study to examine the implications of primary care provider's membership in these models on health of children with neurodevelopmental disorders.

Our study showed that the median age of ASD diagnosis was younger (3.5 years) than the commonly reported median age of diagnosis in the literature (over 4 years) (Christensen et al., 2016; Kleinman et al 2008). In our sample, the age of diagnosis was younger among children with primary care providers with domestic training compared to those with foreign training. After children were identified with delay in development, the time to diagnosis was longer among those with paediatrician as primary care provider compared to those with primary care provider in care models. These findings can be used to inform primary care provider ASD training, specifically focusing on providers with foreign training and paediatricians, as well as targeted primary care interventions to shorten time to diagnosis.

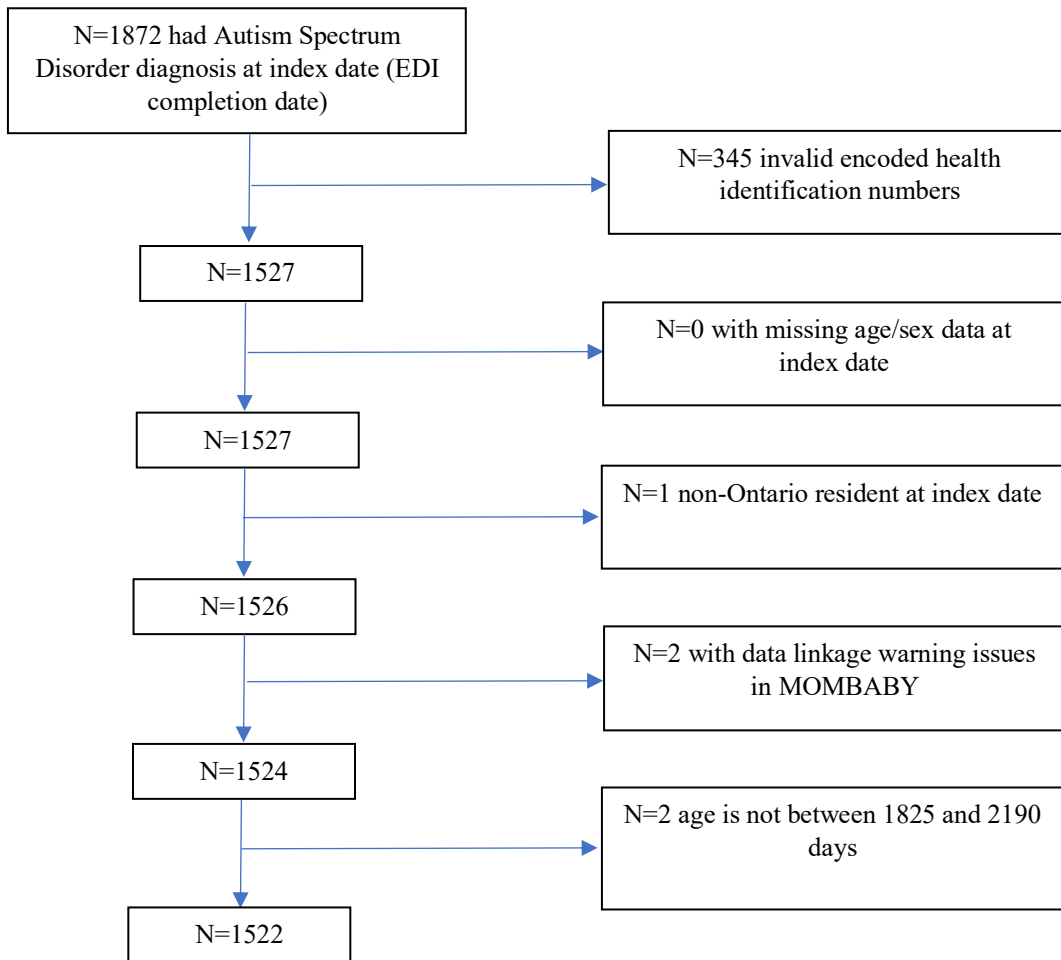


Figure 1: Flowchart detailing inclusion criteria

Table 1: Demographic and primary care provider characteristics of children with Autism Spectrum Disorder on date of Early Development Instrument completion (n=1522)

Demographic characteristics	N (%)
<b>Child characteristics</b>	
Sex	
Male	1240 (81.5)
Female	282 (18.5)
Location of residence	
Urban	1428 (93.8)
Rural and missing*	94 (6.2)
Mother's age at first delivery	
< 19 years	77 (5.7)
≥ 19 years	1277 (94.3)
Missing	168 (11)
Mother's immigration status	
Immigrant	338 (25)
Refugee	43 (3.2)
Non-immigrant	973 (71.9)
Missing	168 (11)
Material deprivation quintile	
1 (least deprived)	318 (21)
2	287 (18.9)
3	268 (17.6)
4	321 (21.1)
5 (most deprived) and missing*	328 (21.6)
Severity of developmental disability**	
Vulnerability in physical health and well-being	
Yes	951 (62.7)
No and missing*	571 (37.5)
Vulnerability in social competence	
Yes	1037 (68.8)
No	474 (31.4)
Missing	11 (0.7)
Vulnerability in emotional maturity	
Yes	1082 (71.4)
No	433 (28.6)
Missing	7 (0.5)
Vulnerability in language and cognitive development	
Yes	628 (41.5)
No	887 (58.6)
Missing	7 (0.5)
Vulnerability in communication and general knowledge	
Yes	1042 (68.6)
No and missing*	478 (31.5)
Overall vulnerability	
Yes	1357 (89.2)
No	165 (10.8)
Comorbidities/technological dependence	
Yes	124 (8.2)
No	1398 (91.9)



Primary care provider characteristics	
Sex	
Male	928 (62.7)
Female	553 (37.3)
No primary care provider	41 (2.7)
Years in practice	
≤ 10 years	54 (3.5)
11-15 years	98 (6.4)
16-20 years	171 (11.2)
21+ years	1158 (76.1)
No primary care provider	41 (2.7)
Location of medical training	
Domestic	909 (59.7)
Foreign	571 (37.5)
No primary care provider	42 (2.8)
Primary care provider membership in primary care models	
Primary care provider in model	965 (63.4)
Primary care provider not in model	88 (5.8)
No primary care provider	41 (2.7)
Paediatrician	428 (28.1)

\*Small cells with 5 or less cases have been combined with another category of a variable – this is done to maintain de-identification only for presenting descriptive statistics; \*\*Indicated by vulnerability on the 5 Early Development Instrument domains; Mean (SD) and median (Q<sub>1</sub>,Q<sub>3</sub>) number of visits children made to their assigned primary care provider were 12.9 (7.8) and 12 (8-17), respectively; Mean (SD) and median (Q<sub>1</sub>,Q<sub>3</sub>) proportion of primary care visits made to primary care provider were 72% (22%) and 75% (56-91%).

Table 2: Age at first Autism Spectrum Disorder diagnosis according to child and primary care provider characteristics for children with and without overall vulnerability on the Early Development Instrument

	Children with overall vulnerability (n=1357) Age of diagnosis available for these children (n=1189)		Children without overall vulnerability (n=165) Age of diagnosis available for these children (n=140)	
	Mean days (SD)	Median (Q <sub>1</sub> ,Q <sub>3</sub> )	Mean days (SD)	Median (Q <sub>1</sub> ,Q <sub>3</sub> )
Overall age at first diagnosis	1333 (446)	1272 (983, 1625)	1266 (390)	1219 (975, 1567)
<b>Child characteristics</b>				
<b>Sex</b>				
Male	1335 (447)	1279 (977, 1623)	1255 (382)	1219 (975, 1567)
Female	1323 (442)	1235 (991, 1644)	1320 (429)	1218 (971, 1597)
<b>Location of residence</b>				
Urban	1335 (445)	1273 (986, 1625)	1277 (390)	1225 (985, 1579)
Rural	1299 (466)	1244 (920, 1644)	968 (269)	1013 (799, 1209)
<b>Mother's age at first delivery</b>				
< 19 years	1366 (470)	1274 (945, 1710)	1295 (495)	1027 (991, 1866)
≥ 19 years	1314 (440)	1254 (972, 1601)	1234 (381)	1208 (943, 1515)
<b>Mother's immigration status</b>				
Immigrant	1311 (419)	1270 (1006, 1569)	1249 (411)	1219 (914, 1515)
Refugee	1381 (456)	1312 (1033, 1693)	894 (0)	894 (894, 894)
Non-immigrant	1316 (450)	1251 (949, 1625)	1235 (375)	1203 (961, 1521)
<b>Material deprivation quintile</b>				
1 (least deprived)	1328 (445)	1288 (976, 1596)	1218 (332)	1204 (959, 1444)
2	1343 (473)	1289 (987, 1663)	1292 (397)	1255 (1003, 1647)
3	1291 (410)	1232 (959, 1580)	1263 (340)	1187 (961, 1584)
4	1308 (431)	1245 (963, 1574)	1222 (525)	1139 (840, 1572)
5 (most deprived)	1394 (465)	1323 (1036, 1687)	1337 (363)	1323 (1027, 1537)
<b>Severity of developmental disability*</b>				
<b>Vulnerability in physical health and well-being</b>				
Yes	1321 (439)	1258 (983, 1621)		
No	1361 (459)	1318 (977, 1648)	1264 (391)	1217 (964, 1561)
<b>Vulnerability in social competence</b>				
Yes	1339 (455)	1268 (983, 1635)		
No	1324 (415)	1292 (995, 1584)	1264 (391)	1217 (964, 1561)
<b>Vulnerability in emotional maturity</b>				
Yes	1335 (448)	1279 (982, 1633)		
No	1333 (437)	1257 (993, 1581)	1264 (391)	1217 (964, 1561)

Vulnerability in language and cognitive development				
Yes	1279 (434)	1209 (951, 1543)		
No	1381 (451)	1379 (1021, 1662)	1264 (391.4)	1217 (964, 1561)
Vulnerability in communication and general knowledge				
Yes	1304 (433)	1250 (974, 1587)		
No	1435 (475)	1449 (1078, 1719)	1264 (391)	1217 (964, 1561)
Comorbidities/technological dependence				
Yes	1371 (484)	1279 (991, 1631)	1302 (379)	1266 (986, 1673)
No	1330 (442)	1271 (977, 1625)	1263 (392)	1213 (964, 1561)
<hr/>				
Primary care provider characteristics				
<hr/>				
Sex				
Male	1330 (450)	1267 (977, 1631)	1241 (366)	1206 (960, 1549)
Female	1322 (430)	1266 (977, 1612)	1271 (411)	1230 (988, 1549)
Years in practice				
≤ 10 years	1334 (493)	1250 (975, 1591)	1230 (394)	1219 (747, 1579)
11-15 years	1322 (437)	1232 (959, 1658)	1204 (300)	1187 (904, 1454)
16-20 years	1296 (408)	1290 (955, 1600)	1364 (438)	1240 (1003, 1695)
21+ years	1332 (445)	1263 (985, 1625)	1243 (381)	1210 (961, 1521)
Location of medical training				
Domestic	1299 (434)	1244 (959, 1599)	1240 (367)	1206 (946, 1576)
Foreign	1367 (450)	1297 (1033, 1642)	1274 (413)	1230 (986, 1515)
Primary care provider membership in primary care models				
Primary care provider in model	1331 (434)	1278 (987, 1621)	1242 (353)	1210 (964, 1572)
Primary care provider not in model	1388 (488)	1314 (982, 1765)	1150 (292)	1114 (842, 1515)
No primary care provider	1629 (527)	1485 (1239, 2127)	1765 (389)	1752 (1436, 2094)
Paediatrician	1306 (451)	1217 (960, 1596)	1281 (434)	1252 (961, 1582)

Table 3: Association between primary care provider and child characteristics and children’s age at first diagnosis of Autism Spectrum Disorder among children with overall vulnerability on the Early Development Instrument (n=1357)

Primary care provider characteristics	Unadjusted analysis (n=1357)			Adjusted analysis† (n=1056)		
	Hazard ratio	95% CI	p Value	Hazard ratio	95% CI	p Value
Sex (Male)						
Female	1.04	0.93, 1.18	0.48	1.07	0.94, 1.22	0.33
Years in practice (≤ 10 years)						
11-15 years	1.10	0.76, 1.59	0.63	1.03	0.68, 1.58	0.88
16-20 years	1.19	0.84, 1.66	0.33	1.04	0.70, 1.53	0.85
21+ years	1.05	0.78, 1.42	0.74	0.96	0.68, 1.37	0.82
Location of medical training (Foreign)						
Domestic	1.17*	1.04, 1.31	0.01	1.17*	1.03, 1.33	0.02
Membership in primary care models (Primary care provider in model)						
No primary care provider	0.57**	0.38, 0.86	0.008			
Primary care provider not in model	0.85	0.66, 1.09	0.20	1.01	0.75, 1.35	0.97
Paediatrician	1.02	0.90, 1.16	0.73	1.07	0.93, 1.23	0.38
<b>Child characteristics</b>						
Sex (Male)						
Female	1.01	0.87, 1.17	0.88	1.00	0.85, 1.17	0.99
Location of residence (Urban)						
Rural	1.06	0.82, 1.36	0.66	0.99	0.76, 1.30	0.97
Mother’s age at first delivery (< 19 years)						
≥ 19 years	1.12	0.87, 1.45	0.39	1.08	0.83, 1.41	0.57
Mother’s immigration status (Non-immigrant)						
Immigrant	1.03	0.90, 1.18	0.66	1.08	0.93, 1.25	0.30
Refugee	0.90	0.65, 1.24	0.50	0.91	0.65, 1.27	0.57
Material deprivation quintile (1(least deprived))						
2	0.93	0.77, 1.12	0.43	0.85	0.69, 1.03	0.09
3	1.12	0.93, 1.34	0.24	1.06	0.88, 1.30	0.53
4	1.05	0.89, 1.25	0.56	1.01	0.84, 1.22	0.91
5 (most deprived)	0.87	0.73, 1.04	0.11	0.88	0.72, 1.07	0.21

Comorbidities/technological dependence (No)						
Yes	0.87	0.71, 1.07	0.19	0.91	0.74, 1.14	0.42

‘No primary care provider’ category from the ‘Membership in primary care models’ variable has been excluded in the adjusted analyses as other primary care provider characteristics were not available for children with no provider; Variables that are independently associated with age of diagnosis are indicated by \* $p < 0.05$  and \*\* $p < 0.01$ ; †In addition to primary care provider and child characteristics, model adjusted for comorbidities and technological dependence; Likelihood ratio of adjusted model:  $p = 0.33$

Table 4: Association between primary care provider and child characteristics and children’s age at first diagnosis of Autism Spectrum Disorder among children without overall vulnerability on the Early Development Instrument (n=165)

Primary care provider characteristics	Unadjusted analysis (n=165)			Adjusted analysis† (n=121)		
	Hazard ratio	95% CI	p Value	Hazard ratio	95% CI	p Value
Sex (Male)						
Female	0.89	0.63, 1.27	0.53	0.71	0.44, 1.15	0.17
Years in practice (≤ 10 years)						
11-15 years	1.18	0.41, 3.36	0.76	0.85	0.16, 4.42	0.85
16-20 years	0.60	0.24, 1.53	0.29	0.52	0.11, 2.51	0.41
21+ years	0.92	0.43, 1.97	0.82	0.60	0.16, 2.32	0.46
Location of medical training (Foreign)						
Domestic	1.15	0.80, 1.67	0.45	1.05	0.61, 1.81	0.85
Membership in primary care models (Primary care provider in model)						
No primary care provider	0.31*	0.11, 0.88	0.03			
Primary care provider not in model	1.46	0.67, 3.17	0.34	1.96	0.69, 5.55	0.21
Paediatrician	0.81	0.57, 1.17	0.27	0.89	0.56, 1.41	0.60
Child characteristics						
Sex (Male)						
Female	0.86	0.55, 1.35	0.50	0.89	0.51, 1.55	0.69
Location of residence (Urban)						
Rural	2.79*	1.12, 6.92	0.03	1.98	0.74, 5.27	0.17

Mother's age at first delivery (< 19 years)						
≥ 19 years	1.20	0.38, 3.79	0.76	1.01	0.24, 4.28	0.99
Mother's immigration status (Non-immigrant)						
Immigrant	0.88	0.58, 1.34	0.56	1.02	0.56, 1.87	0.94
Refugee	4.85	0.65, 35.98	0.12	5.43	0.66, 44.57	0.12
Material deprivation quintile (1(least deprived))						
2	0.76	0.48, 1.20	0.24	0.85	0.48, 1.52	0.59
3	0.87	0.50, 1.53	0.63	0.82	0.43, 1.57	0.55
4	0.74	0.42, 1.28	0.28	0.96	0.49, 1.88	0.91
5 (most deprived)	0.72	0.42, 1.22	0.22	0.67	0.33, 1.36	0.27
Comorbidities/technological dependence (No)						
Yes	0.99	0.52, 1.89	0.98	0.85	0.41, 1.76	0.66

'No primary care provider' category from the 'Membership in primary care models' variable has been excluded in the adjusted analyses as other primary care provider characteristics were not available for children with no provider; †In addition to primary care provider and child characteristics, model adjusted for comorbidities and technological dependence; Likelihood ratio of adjusted model:  $p=0.80$

Table 5: Length of time between age at first identification of delay in development to age at first diagnosis of Autism Spectrum Disorder according to child and primary care provider characteristics (n=1157)

	Children who received ASD diagnosis after being identified with delay in development (n=967)		Children who received ASD diagnosis before being identified with delay in development (n=190)	
	Mean days (SD)	Median (Q <sub>1</sub> ,Q <sub>3</sub> )	Mean days (SD)	Median (Q <sub>1</sub> ,Q <sub>3</sub> )
Overall time between age at first identification of delay in development and age at first diagnosis	516 (452)	388 (154, 744)	369 (399)	211 (76, 549)
Child characteristics				
Sex				
Male	511 (446)	384 (157, 731)	364 (402)	203 (71, 549)
Female	537 (479)	416 (151, 816)	417 (369)	314 (151, 539)
Location of residence				
Urban	511 (449)	385 (153, 736)	375 (395)	213 (81, 569)
Rural	622 (518)	480 (241, 987)	282 (470)	110 (29, 336)

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Mother's age at first delivery				
< 19 years	504 (480)	349 (157, 704)	476 (252)	438 (253, 700)
≥ 19 years	526 (454)	406 (161, 770)	373 (417)	195 (74, 587)
Mother's immigration status				
Immigrant	515 (444)	369 (154, 770)	406 (422)	195 (67, 760)
Refugee	536 (391)	496 (138, 789)	162 (72)	193 (80, 213)
Non-immigrant	529 (463)	416 (166, 748)	375 (415)	213 (76, 556)
Material deprivation quintile				
1 (least deprived)	501 (433)	407 (148, 749)	333 (327)	233 (66, 563)
2	515 (475)	368 (133, 736)	405 (484)	180 (96, 639)
3	459 (395)	360 (165, 613)	379 (395)	180 (60, 665)
4	521 (438)	421 (163, 772)	379 (408)	216 (74, 547)
5 (most deprived)	573 (501)	436 (194, 862)	353 (393)	195 (77, 469)
Severity of developmental disability				
Vulnerability in physical health and well-being				
Yes	548 (483)	429 (158, 786)	340 (371)	194 (82, 459)
No	455 (382)	336 (149, 679)	418 (437)	233 (70, 636)
Vulnerability in social competence				
Yes	517 (460)	383 (153, 752)	366 (401)	213 (75, 548)
No	514 (432)	403 (158, 741)	378 (395)	207 (80, 569)
Vulnerability in emotional maturity				
Yes	512 (451)	380 (149, 770)	376 (410)	214 (73, 553)
No	526 (458)	416 (158, 722)	348 (362)	192 (86, 549)
Vulnerability in language and cognitive development				
Yes	527 (480)	384 (147, 772)	353 (405)	185 (74, 459)
No	508 (431)	393 (161, 728)	380 (395)	214 (81, 569)
Vulnerability in communication and general knowledge				
Yes	512 (451)	385 (154, 739)	369 (414)	193 (77, 539)
No	523 (456)	388 (158, 744)	372 (357)	252 (62, 569)
Comorbidities/technological dependence				
Yes	706 (537)	582 (322, 1037)	255 (375)	170 (81, 213)
No	495 (437)	370 (149, 721)	377 (400)	214 (74, 569)
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Primary care provider characteristics				
Sex				
Male	522 (445)	407 (161, 775)	388 (387)	231 (76, 613)
Female	502 (460)	381 (146, 722)	346 (418)	176 (71, 476)
Years in practice				
≤ 10 years	414 (591)	175 (92, 440)	431 (419)	213 (93, 668)
11-15 years	409 (335)	359 (139, 649)	382 (450)	185 (47, 587)
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16-20 years	444 (389)	319 (124, 673)	458 (456)	253 (114, 651)
21+ years	537 (458)	419 (161, 784)	345 (383)	195 (71, 536)
Location of medical training				
Domestic	483 (423)	360 (141, 724)	417 (427)	251 (77, 644)
Foreign	562 (484)	440 (179, 784)	274 (320)	163 (74, 361)
Primary care provider membership in primary care models				
Primary care provider in model	487 (449)	354 (146, 686)	394 (412)	219 (91, 598)
Primary care provider not in model	451 (519)	223 (115, 677)	330 (354)	214 (51, 587)
No primary care provider	564 (571)	352 (198, 873)	376 (245)	376 (203, 549)
Paediatrician	579 (436)	479 (230, 832)	289 (366)	162 (59, 362)

\*Length of time between identification of delay in development and age at Autism Spectrum Disorder diagnosis available for 1157 children; Absolute differences in time between age at first identification of delay in development to age at first diagnosis of Autism Spectrum Disorder are presented



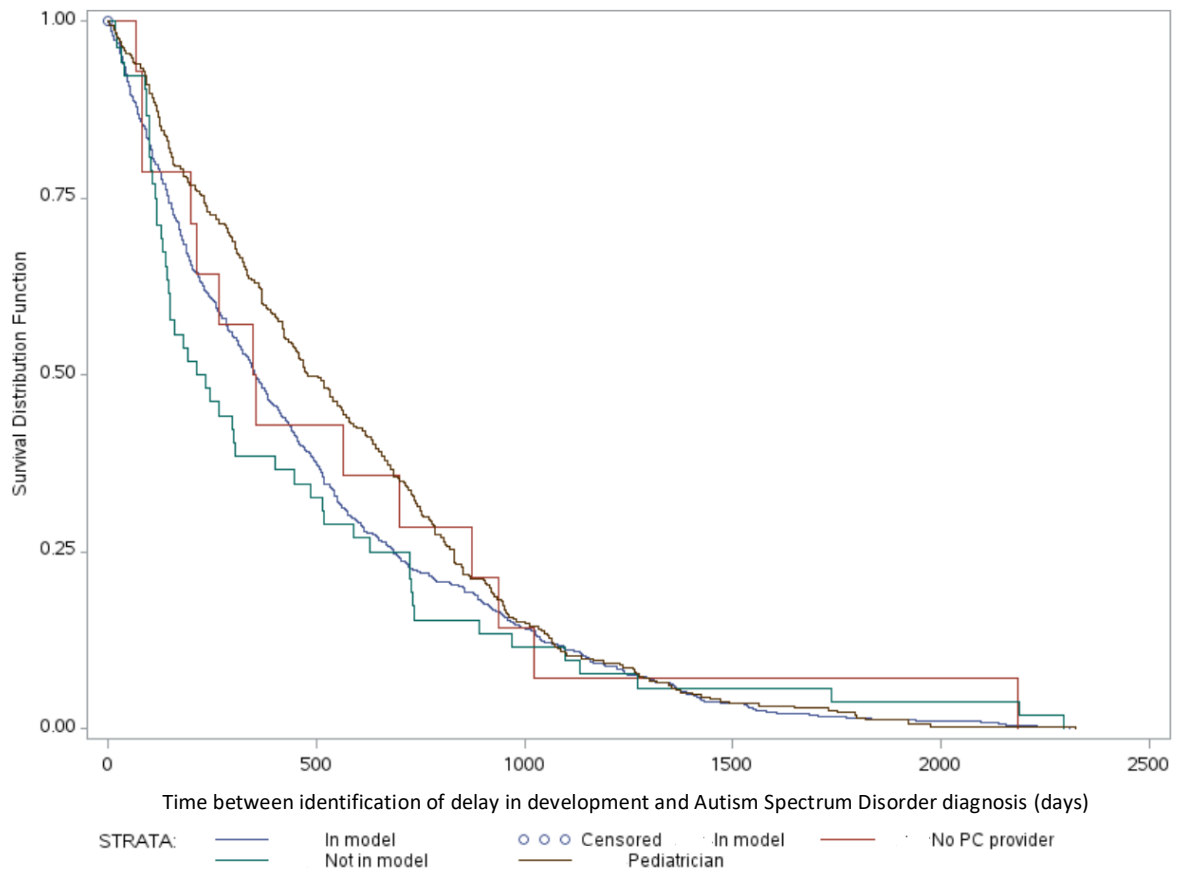


Figure 2: Kaplan Meier curves examining probability of Autism Spectrum Disorder diagnosis after identification of delay in development according to primary care provider’s membership in care models (includes children who received ASD diagnosis after identification of delay in development and children who received diagnosis before identification of this delay) (n=1157)

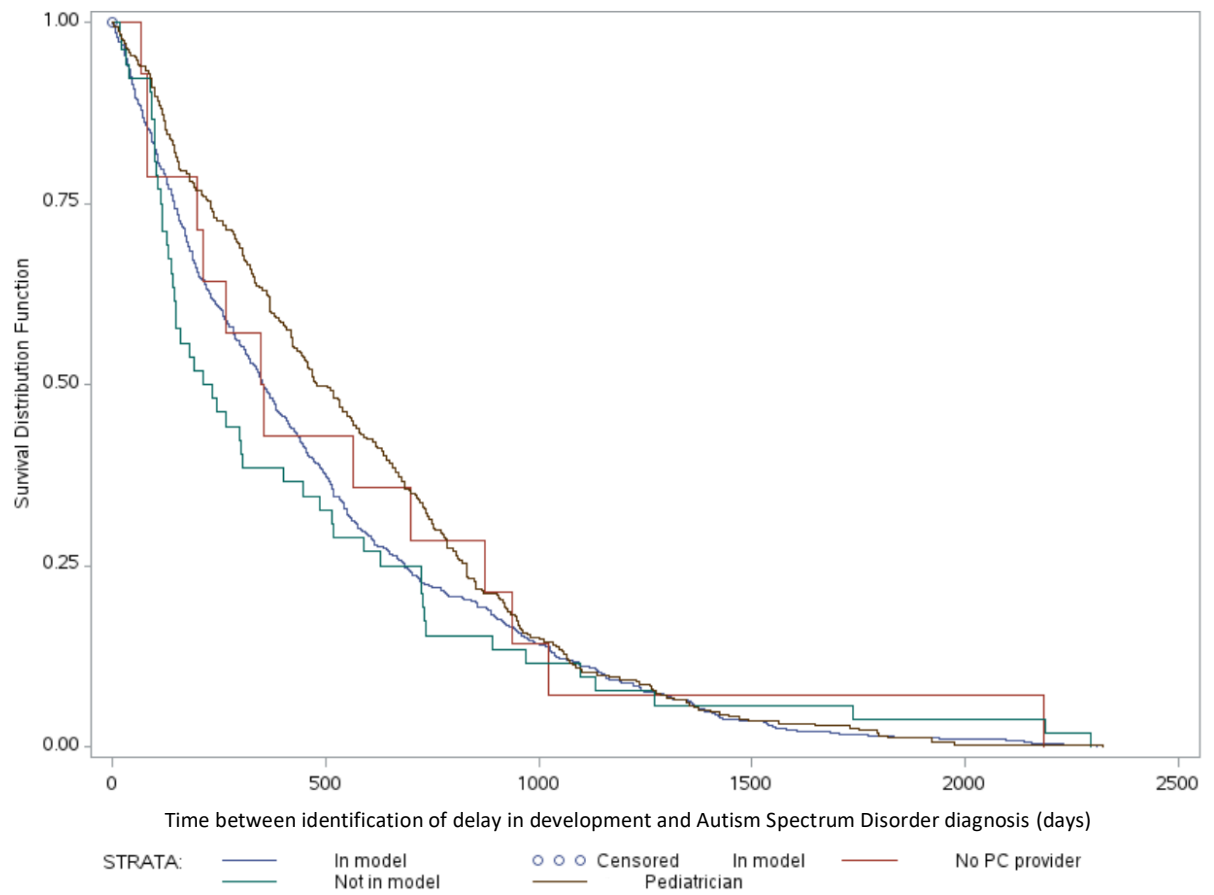


Figure 3: Kaplan Meier curves examining probability of Autism Spectrum Disorder diagnosis after identification of delay in development according to primary care provider’s membership in care models (includes only children who received diagnosis after identification of delay in development) (n=967)

Table 6: Association between primary care provider and child characteristics and age at first diagnosis of Autism Spectrum Disorder after being identified with delay in development (includes children who received diagnosis after identification of delay in development and children who received diagnosis before identification of this delay) (n=1157)

Primary care provider characteristics	Unadjusted analysis (n=1157)			Adjusted analysis† (n=865)		
	Hazard ratio	95% CI	p Value	Hazard ratio	95% CI	p Value
Sex (Male)						
Female	1.09	0.90, 1.17	0.68	1.02	0.88, 1.18	0.77
Years in practice (≤ 10 years)						
11-15 years	1.11	0.71, 1.76	0.65	1.44	0.82, 2.50	0.20
16-20 years	1.00	0.66, 1.52	0.99	1.39	0.82, 2.35	0.23
21+ years	0.80	0.55, 1.17	0.26	1.14	0.70, 1.87	0.60
Location of medical training (Foreign)						
Domestic	1.20*	1.05, 1.37	0.01	1.08	0.87, 1.34	0.50
Location of medical training*duration of time between age at first identification of delay in development and age at first diagnosis	1.00*	1.00, 1.00	0.01	1.00	1.00, 1.00	0.62
Membership in primary care models (Primary care provider in model)						
No primary care provider	0.85	0.50, 1.45	0.55			
Primary care provider not in model	1.05	0.79, 1.40	0.74	1.18	0.85, 1.64	0.33
Paediatrician	0.84*	0.73, 0.97	0.01	0.88	0.75, 1.03	0.11
Child characteristics						
Sex (Male)						
Female	0.93	0.79, 1.10	0.41	0.96	0.80, 1.14	0.62
Location of residence (Urban)						
Rural	0.80	0.59, 1.10	0.17	0.75	0.53, 1.05	0.09

Mother's age at first delivery (< 19 years)						
≥ 19 years	0.96	0.72, 1.27	0.77	0.84	0.62, 1.12	0.23
Mother's immigration status (Non-immigrant)						
Immigrant	1.04	0.90, 1.21	0.60	1.04	0.88, 1.22	0.67
Refugee	1.02	0.71, 1.45	0.93	1.08	0.75, 1.56	0.67
Material deprivation quintile (1(least deprived))						
2	0.97	0.79, 1.18	0.73	0.98	0.79, 1.21	0.85
3	1.11	0.91, 1.36	0.31	1.05	0.84, 1.31	0.65
4	0.97	0.79, 1.17	0.72	0.94	0.76, 1.17	0.58
5 (most deprived)	0.86	0.71, 1.04	0.11	0.89	0.72, 1.11	0.30
Severity of developmental disability						
Vulnerability in physical health and well-being (No)						
Yes	0.80**	0.70, 0.91	0.001	0.79**	0.68, 0.93	0.004
Vulnerability in social competence (No)						
Yes	0.99	0.86, 1.13	0.85	0.99	0.83, 1.18	0.87
Vulnerability in emotional maturity (No)						
Yes	1.04	0.90, 1.20	0.60	1.08	0.91, 1.29	0.37
Vulnerability in language and cognitive development (No)						
Yes	0.95	0.84, 1.08	0.44	1.04	0.88, 1.22	0.66
Vulnerability in communication and general knowledge (No)						
Yes	1.03	0.90, 1.19	0.64	1.04	0.88, 1.22	0.66
Comorbidities/ technological dependence (No)						
Yes	0.66***	0.53, 0.82	0.0001	0.76*	0.61, 0.96	0.02

'No primary care provider' category from the 'Membership in primary care models' variable has been excluded in the adjusted analyses as other primary care provider characteristics were not available for children with no provider; Variables that are independently associated with age of diagnosis are indicated by \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ ; † In addition to primary care provider and child characteristics, model

adjusted for severity of developmental disability, comorbidities and technological dependence; Likelihood ratio of adjusted model:  $p=0.01$ ; Location of medical training violated proportional hazards assumption, thus, an interaction term was created between this variable and duration of time between age at first identification of delay in development and age at first diagnosis.

Table 7: Association between primary care provider and child characteristics and age at first diagnosis of Autism Spectrum Disorder after being identified with delay in development (includes children who received diagnosis after identification of delay in development) (n=967)

Primary care provider characteristics	Unadjusted analysis (n=967)			Adjusted analysis† (n=865)		
	Hazard ratio	95% CI	<i>p</i> Value	Hazard ratio	95% CI	<i>p</i> Value
Sex (Male)						
Female	1.03	0.90, 1.17	0.68	1.02	0.88, 1.18	0.78
Years in practice (≤ 10 years)						
11-15 years	1.11	0.71, 1.76	0.65	1.41	0.80, 2.46	0.23
16-20 years	1.00	0.66, 1.52	0.99	1.35	0.80, 2.29	0.26
21+ years	0.80	0.55, 1.17	0.26	1.23	0.69, 1.85	0.63
Location of medical training (Foreign)						
Domestic	1.20**	1.05, 1.37	0.006	1.13	0.97, 1.31	0.11
Membership in primary care models* time difference between age at first identification of delay in development and age at first ASD diagnosis	1.00	1.00, 1.00	0.83	1.00**	1.00, 1.00	0.003
Membership in primary care models (Primary care provider in model)						
No primary care provider	0.85	0.50, 1.45	0.55			
Primary care provider not in model	1.05	0.79, 1.40	0.74	0.99	0.70, 1.41	0.96
Paediatrician	0.84*	0.73, 0.97	0.01	0.68**	0.54, 0.86	0.001
Child characteristics						
Sex (Male)						

Female	0.93	0.79, 1.10	0.41	0.92	0.77, 1.10	0.37
Location of residence (Urban)						
Rural	0.80	0.59, 1.10	0.17	0.74	0.53, 1.03	0.08
Mother's age at first delivery (< 19 years)						
≥ 19 years	0.96	0.72, 1.27	0.77	0.86	0.64, 1.16	0.32
Mother's immigration status (Non-immigrant)						
Immigrant	1.04	0.90, 1.21	0.60	1.01	0.86, 1.19	0.88
Refugee	1.02	0.71, 1.45	0.93	1.05	0.73, 1.52	0.79
Material deprivation quintile (1 (least deprived))						
2	0.97	0.79, 1.18	0.73	0.97	0.78, 1.20	0.77
3	1.11	0.91, 1.36	0.31	1.05	0.84, 1.30	0.70
4	0.97	0.79, 1.17	0.72	0.93	0.75, 1.16	0.52
5 (most deprived)	0.86	0.71, 1.04	0.11	0.89	0.71, 1.11	0.29
Severity of developmental disability						
Vulnerability in physical health and well-being (No)						
Yes	0.80**	0.70, 0.91	0.001	0.79**	0.66, 0.91	0.002
Vulnerability in social competence (No)						
Yes	0.99	0.86, 1.13	0.95	0.96	0.80, 1.15	0.63
Vulnerability in emotional maturity (No)						
Yes	1.04	0.90, 1.20	0.60	1.09	0.91, 1.30	0.35
Vulnerability in language and cognitive development (No)						
Yes	0.95	0.84, 1.08	0.44	1.03	0.87, 1.21	0.76
Vulnerability in communication and general knowledge (No)						
Yes	1.03	0.90, 1.19	0.64	1.14	0.95, 1.35	0.15
Comorbidities/ technological dependence (No)						
Yes	0.66***	0.53, 0.82	0.0001	0.72**	0.57, 0.91	0.006

‘No primary care provider’ category from the ‘Membership in primary care models’ variable has been excluded in the adjusted analyses as other primary care provider characteristics were not available for children with no provider; Variables that are independently associated with age of diagnosis are indicated by \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ ; † In addition to primary care provider and child characteristics, model adjusted for severity of developmental disability, comorbidities and technological dependence; Likelihood ratio of adjusted model:  $p = 0.0005$ ; Membership in primary care models violated proportional hazards assumption, thus, an interaction term was created between this variable and duration of time between age at first identification of delay in development and age at first diagnosis. While this interaction term was significant in the adjusted model ( $p < 0.01$ ), it was not clinically meaningful as the hazard ratio (95% CI) was 1.00 (1.00, 1.00). This may be attributable to the marginal violation of the proportional hazard assumption by this variable ( $p = 0.04$ ).

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#### Appendix 1: Primary care visit codes

In the Ontario Health Insurance Plan Claims database (OHIP), all visits with spec=00 [GP], 05 [comm med], 26 [pediatrician] for the following fee codes: A001, A002, A003, A004, A005, A006, A007, A008, A901, A903, A905, G212, G271, G372, G373, G365, G538, G539, G590, G591, G840, G841, G842, G843, G844, G845, G846, G847, G848, K005, K013, K017, A261, A262, A268, K267, K269, K119, K120 – Core Primary Care Codes AND location = office, home, phone were used to determine primary care visits.

#### Appendix 2: Autism Spectrum Disorder diagnosis codes

In the Ontario Health Insurance Plan Claims database (OHIP), where DXCODE = 299 (childhood psychoses (e.g. autism)) was used.

In the National Ambulatory Care Reporting System (NACRS), and the Discharge Abstract Database (DAD), ICD10 codes: F84.x were used (these codes were examined across DX10CODE1-DX10CODE10 for NACRS and DX10CODE1-DX10CODE25 for DAD).

#### Appendix 3: Delay in development diagnosis codes

In the Ontario Health Insurance Plan Claims database (OHIP), where DXCODE = 296, 298, 300, 301, 302, 306, 307, 309, 311, 313, 314, 315, 319, 904, 909 were used.

The following codes were examined across DX10CODE1-DX10CODE10 for the National Ambulatory Care Reporting System (NACRS) and DX10CODE1-DX10CODE25 for the Discharge Abstract Database (DAD): F063, F067, F34, F38, F39, F70, F80, F81, F82, F83, F88, F89, F90, F91, F92, F93, F94, F95, F98, F99, F348, F349, F380, F381, F388, F401, F444, F602, F710, F711, F718, F719, F720, F721, F728, F729, F730, F731, F738, F739, F780, F781, F788, F789, F790, F791, F798, F799, F800, F801, F802, F808, F809, F818, F819, F900, F901, F908, F909, F910, F911, F912, F913, F918, F919, F920, F928, F929, F930, F931, F932, F933, F938, F939, F940, F941, F942, F948, F949, F950, F951, F952, F958, F959, F982, F983, F984, F985, F986, F988, F989, G122, G600, G1228, G1229, H54, H55, H57, H90, H91, H533, H534, H535, H536, H538, H539, H540, H541, H542, H543, H544, H545, H546, H547, H549, H570, H900, H901, H902, H903, H904, H905, H906, H907, H908, H910, H912, H913, H918, H919, H932, K100, Q16, Q169, R41, R47, R62, R416, R478, R620, R628, R629, R633, R4188, Z603, Z734, Z735

Appendix 4: Age at first diagnosis of Autism Spectrum Disorder according to child and primary care provider characteristics (n=1329)

	Mean days (SD)	Median (Q <sub>1</sub> ,Q <sub>3</sub> )
Overall age at first diagnosis	1326 (440)	1263 (983, 1620)
<b>Child characteristics</b>		
Sex		
Male	1327 (441)	1272 (977, 1617)
Female	1322 (440)	1235 (986, 1644)
Location of residence		
Urban	1329 (439)	1269 (986, 1621)
Rural	1275 (462)	1220 (915, 1605)
Mother's age at first delivery		
< 19 years	1362 (467)	1269 (946, 1710)
≥ 19 years	1306 (435)	1251 (965, 1596)
Mother's immigration status		
Immigrant	1305 (418)	1260 (987, 1568)
Refugee	1369 (457)	1303 (987, 1693)
Non-immigrant	1307 (443)	1242 (954, 1614)
Material deprivation quintile		
1 (least deprived)	1314 (433)	1271 (975, 1576)
2	1335 (461)	1284 (991, 1663)
3	1289 (404)	1216 (959, 1582)
4	1301 (439)	1238 (943, 1573)
5 (most deprived)	1389 (457)	1323 (1036, 1681)
Severity of developmental disability		
Vulnerability in physical health and well-being		
Yes	1321 (439)	1258 (983, 1621)
No	1333 (442)	1272 (977, 1617)
Vulnerability in social competence		
Yes	1339 (455)	1268 (983, 1635)
No	1304 (408)	1263 (986, 1579)
Vulnerability in emotional maturity		
Yes	1335 (448)	1279 (982, 1633)
No	1306 (421)	1239 (986, 1578)
Vulnerability in language and cognitive development		
Yes	1279 (434)	1209 (951, 1543)
No	1360 (443)	1339 (997, 1647)
Vulnerability in communication and general knowledge		
Yes	1304 (433)	1250 (974, 1587)

Comorbidities/technological dependence	No	1377 (455)	1365 (1002, 1673)
	Yes	1365 (474)	1279 (989, 1652)
	No	1323 (437)	1263 (977, 1619)
<hr/>			
Primary care provider characteristics			
<hr/>			
Sex			
	Male	1321 (442)	1255 (976, 1623)
	Female	1317 (428)	1261 (982, 1600)
Years in practice			
	≤ 10 years	1320 (479)	1248 (968, 1585)
	11-15 years	1312 (427)	1224 (948, 1647)
	16-20 years	1302 (409)	1272 (964, 1601)
	21+ years	1322 (440)	1257 (984, 1619)
Location of medical training			
	Domestic	1292 (427)	1238 (959, 1596)
	Foreign	1359 (447)	1289 (1020, 1630)
Membership in primary care models			
	Primary care provider in model	1323 (428)	1269 (987, 1616)
	Primary care provider not in model	1366 (477)	1289 (975, 1677)
	No primary care provider	1649 (505)	1493 (1267, 2127)
	Paediatrician	1303 (448)	1225 (960, 1596)

\*Age of Autism Spectrum Disorder diagnosis available for 1329 children



Appendix 5: Demographic and primary care provider characteristics of children with Autism Spectrum Disorder with missing data for maternal age and immigration status on date of Early Development Instrument completion (n=168)

Demographic characteristics	N (%)
<b>Child characteristics</b>	
Sex	
Male	139 (82.7)
Female	29 (17.3)
Location of residence	
Urban	161 (95.8)
Rural and missing	7 (4.2)
Material deprivation quintile	
1 (least deprived)	34 (20.2)
2	32 (19.1)
3	19 (11.3)
4	34 (20.2)
5 (most deprived) and missing	49 (28.17)
Severity of developmental disability	
Vulnerability in physical health and well-being	
Yes	101 (60.1)
No and missing	67 (39.9)
Vulnerability in social competence	
Yes	120 (71.4)
No and missing	48 (28.6)
Vulnerability in emotional maturity	
Yes	123 (73.2)
No	45 (26.8)
Vulnerability in language and cognitive development	
Yes	75 (44.6)
No	93 (55.4)
Vulnerability in communication and general knowledge	
Yes	115 (68.5)
No	53 (31.6)
Comorbidities/technological dependence	
Yes	7 (4.2)
No	161 (95.8)
<b>Primary care provider characteristics</b>	
Sex	
Male	88 (61.5)
Female	55 (38.5)
Years in practice	
≤ 10 years	15 (8.9)
11-15 years	34 (20.2)
16-20 years	16 (9.5)
21+ years	103 (61.3)
Location of medical training	
Domestic and missing	96 (57.1)
Foreign	72 (42.9)

Membership in primary care enrolment models	
Primary care provider in enrolment model	91 (54.2)
Primary care provider not in enrolment model	22 (13.1)
No primary care provider	25 (14.9)
Paediatrician	30 (17.9)

Appendix 6: Association between primary care provider and child characteristics and children’s age at first diagnosis of Autism Spectrum Disorder

Primary care provider characteristics	Unadjusted analysis (n=1522)			Adjusted analysis† (n=1329)		
	Hazard ratio	95% CI	p Value	Hazard ratio	95% CI	p Value
Sex (Male)						
Female	1.03	0.92, 1.15	0.62	1.04	0.92, 1.18	0.51
Years in practice (≤ 10 years)						
11-15 years	1.08	0.76, 1.53	0.66	1.15	0.75, 1.75	0.52
16-20 years	1.12	0.82, 1.54	0.49	1.11	0.75, 1.64	0.60
21+ years	1.03	0.78, 1.37	0.82	1.06	0.74, 1.51	0.75
Location of medical training (Foreign)						
Domestic	1.17**	1.05, 1.31	0.006	1.21**	1.07, 1.37	0.003
Membership in primary care models (Primary care provider in model)						
No primary care provider	0.55**	0.37, 0.81	0.002			
Primary care provider not in model	0.87	0.69, 1.11	0.26	1.09	0.83, 1.44	0.54
Paediatrician	1.01	0.90, 1.14	0.87	1.07	0.94, 1.23	0.32
<b>Child characteristics</b>						
Sex (Male)						
Female	0.99	0.86, 1.14	0.92	0.92	0.79, 1.07	0.29
Location of residence (Urban)						
Rural	1.09	0.86, 1.39	0.48	0.96	0.74, 1.25	0.76
Mother’s age at first delivery (< 19 years)						
≥ 19 years	1.14	0.88, 1.56	0.32	1.20	0.92, 1.56	0.18
Mother’s immigration status (Non-immigrant)						
Immigrant	1.02	0.90, 1.16	0.76	1.01	0.88, 1.16	0.89
Refugee	0.89	0.65, 1.23	0.49	0.87	0.62, 1.21	0.41
Material deprivation quintile (1(least deprived))						
2	0.92	0.78, 1.09	0.34	0.83	0.69, 1.00	0.05

3	1.09	0.91, 1.29	0.35	1.02	0.85, 1.23	0.85
4	1.02	0.86, 1.20	0.84	0.95	0.79, 1.14	0.57
5 (most deprived)	0.85	0.72, 1.00	0.05	0.81*	0.67, 0.98	0.03
Severity of developmental disability						
Vulnerability in physical health and well-being (No)						
Yes	1.03	0.92, 1.15	0.62	1.03	0.90, 1.18	0.68
Vulnerability in social competence (No)						
Yes	0.90	0.80, 1.01	0.08	0.80**	0.68, 0.94	0.006
Vulnerability in emotional maturity (No)						
Yes	0.92	0.82, 1.04	0.20	0.92	0.79, 1.07	0.28
Vulnerability in language and cognitive development (No)						
Yes	1.18**	1.06, 1.32	0.003	1.24**	1.07, 1.43	0.005
Vulnerability in communication and general knowledge (No)						
Yes	1.17*	1.04, 1.31	0.01	1.20*	1.03, 1.4	0.02
Comorbidities/technological dependence (No)						
Yes	0.88	0.72, 1.07	0.19	0.88	0.72, 1.08	0.23

‘No primary care provider’ category from the ‘Membership in primary care models’ variable has been excluded in the adjusted analyses as other primary care provider characteristics were not available for children with no provider; Variables that are independently associated with age of diagnosis are indicated by \* $p < 0.05$  and \*\* $p < 0.01$ ; † In addition to primary care provider and child characteristics, model adjusted for severity in developmental disability, comorbidities and technological dependence; Likelihood ratio of adjusted model:  $p = 0.003$

## **Chapter Five: Discussion**

There is significant evidence indicating that the strong relationship between SES and health appears to have its roots in childhood (Allin & Stabile, 2012). Among children with neurodevelopmental disorders, the impact of SES on health of children with ASD remains poorly understood. To our knowledge, this is the first study examining the relationship between neighbourhood SES and health of children with ASD through a pan-Canadian approach. The first paper of this thesis established the demographic and developmental health profile of children with ASD, which helped contextualize the findings of the subsequent papers. The second paper demonstrated the relationship between neighbourhood SES and developmental health of children with this disorder using several analytical methods. The third paper identified primary care provider characteristics associated with age at first diagnosis of ASD. This discussion is a synthesis of the three papers in the context of existing body of literature on children with ASD with suggested implications of the combined findings.

### **3.1 Synthesis of Study Findings**

The findings of this thesis contribute to the most recent prevalence estimates of children with ASD provided by the National Autism Spectrum Disorder Surveillance System in 2015 (Public Health Agency of Canada, 2018) by focusing on children in kindergarten in the context of neighbourhoods where they live. In this study, we used a custom boundary definition to identify neighbourhoods (Forer et al. 2019; Guhn et al., 2016). Across all provinces and territories in Canada except Northwest Territories, there were between 10.1% (Ontario) and 40% (Saskatchewan) of neighbourhoods with no

children with ASD. The number of children with ASD in a neighbourhood ranged from none to as high as 21 (Ontario) across provinces and territories. The proportions of neighbourhoods with different levels of spatial clusters of children with this disorder also varied across provinces and territories. There were greater proportions of neighbourhoods with three or fewer children with ASD compared to those with four or five. Notably, there was no linear relationship between the size of spatial cluster and developmental vulnerability of children with ASD as hypothesized; instead, the proportions of children with this disorder demonstrating developmental vulnerability did not decrease with size of spatial cluster. These findings highlight the importance of taking a jurisdiction specific approach to service planning, as not only the prevalence of children with ASD vary across provinces and territories, but also the trend in developmental health in relation to the size of spatial cluster of children with this disorder.

The rising prevalence of ASD has led to increasing demands from the health, education, and community service systems, making it more challenging to access necessary services (Hodgetts, Zwaigenbaum, & Nicholas, 2015). Given this increasing demand on current service systems, recommendations for a national strategy to address ASD service provision across childhood have been made in Canada (Hodgetts et al., 2015). Despite the increased public funding for early intensive intervention for children with ASD across many provinces, the provision of these services varies across provinces along several dimensions (Shepherd & Waddell, 2015). These include the relative mix of public and private funding, the level of integration among services, and the extent of population coverage (Shepherd & Waddell, 2015). For example, in Nova Scotia, public

intervention services are provided to all young children with ASD, although considerable waitlists hinder timely access to services (Volden et al., 2015). British Columbia and Alberta subsidize the cost of private interventions, where the program in British Columbia provides funding to families of children with ASD, whereas the program in Alberta is integrated with financial support for all families of children with developmental disabilities (Volden et al., 2015). Across provinces, families can choose to seek services from the private sector if they are able to afford it, when publicly funded services are considered limited or inaccessible (Volden et al., 2015). While there is significant provincial heterogeneity in the services provided to children with ASD, they all continue to be offered based on the needs of individual children. Findings of this thesis can help enhance the current service delivery approach as they highlight the developmental health needs of groups of children living in neighbourhoods, which is crucial for reducing population level inequalities in health of children with ASD. For example, our findings regarding the average developmental vulnerability of children living in neighbourhoods with different levels of spatial clusters of children with ASD can help determine the volume of early intervention services to provide in neighbourhoods with differing numbers of children with this disorder. In addition to targeting appropriate populations for service coverage, our findings can also support customized service planning, including the level of integration between services from different specialties, as vulnerabilities in different areas of development (e.g. physical health and well-being and language and cognitive development) have been identified in relation to spatial clusters.

Neighbourhoods represent important geographic units of study in the context of child development. There is a significant body of literature showing a strong association between neighbourhood level affluence or poverty and early childhood development (Forer et al., 2019; Zeraatkar et al., 2020). Previously, it has been found that vulnerabilities in children's developmental health can differ across neighbourhoods, with vulnerability rates ranging from less than 5% to above 50% (Guhn et al., 2016). The majority of evidence on impact of neighbourhood level factors on health comes from the U.S., and to a lesser degree, Europe (O'Campo et al., 2015). Our knowledge of the extent to which these findings apply to the Canadian context remains limited (O'Campo et al., 2015). For example, it has been found that concentrated poverty and high levels of urban social disorder well documented in U.S. cities are present at a lower degree in Canada (Sampson, Raudenbush, & Earls, 1997; Oreopoulos, 2008; Parsons et al., 2010). However, income inequalities have been growing between neighbourhoods in large urban cities in Canada, highlighting the importance of examining the impact of neighbourhood SES on health of those living in this country (Oreopoulos, 2008; Hulchanski, 2010).

The results of this thesis corroborate the now common finding that neighbourhood disadvantage is a significant determinant of health outcomes (O'Campo et al., 2015). Notably, this thesis provides a nuanced understanding of the relationship between neighbourhood SES and development of children with ASD by demonstrating that this relationship varies across provinces and territories based on the unit of analysis (individual child versus neighbourhood), as well as the analytical approach (single level model approach versus multilevel model approach). Although the multilevel model

approach, where a child with ASD was the unit of analysis, for a pan-Canadian analysis showed higher neighbourhood SES was associated with lower odds of developmental vulnerability, this trend was not observed in every province and territory in the province-specific analysis. Furthermore, in the neighbourhood level ecological approach, where the neighbourhood was the unit of analysis, higher neighbourhood SES was associated with lower percentage of children with developmental vulnerability only in Ontario. These findings emphasize that although living in affluent neighbourhoods is associated with better development among children with ASD, this is not the case for every area of development in every province and territory. Our findings also illustrate the importance of focusing on the appropriate unit of analysis when making service planning decisions. The value of the multilevel model approach is particularly emphasized for protecting health of populations in different geographic areas, as it considers clustering of children with ASD in neighbourhoods, hence capturing their health in the context in which they live (Leyland & Groenewegen, 2003).

While neighbourhood deprivation was associated with vulnerability in several areas of development in many provinces and territories, this trend was not observed in Nova Scotia, where higher neighbourhood SES was associated with higher likelihood of demonstrating vulnerability in two areas of development (Social Competence and Communication Skills and General Knowledge). Although there is no published evidence, it is possible that children living in low SES neighbourhoods in Nova Scotia may not have adequate access to early identification services thus may be underrepresented in our sample. The finding from Nova Scotia also highlights the



pathways through which neighbourhood deprivation influences different areas of development of children with ASD may not be the same in every province and territory. A significant body of literature suggests multiple mechanisms explain the impact of SES on health (Braveman & Gottlieb, 2014). There is increasing evidence indicating that the causal relationship between SES and health includes direct relationships as well as complex pathways that involve biopsychosocial processes (Miller et al., 2009). Some aspects of SES can impact health over a short period of time through direct and rapid acting exposures, such as exposure to lead in substandard housing which leads to low cognitive function and stunted physical development among exposed children (Lidsky & Schneider, 2003; Afeiche et al., 2012). Other aspects of SES may impact health indirectly while manifesting through pathways that also occur during a short period of time, such as availability of alcohol in low SES neighbourhoods which can influence its use in young people, thereby determining rates of alcohol-related traumatic injury in this sub-population (Pollack, Cubbin, Ahn, & Winkleby, 2005).

Notwithstanding the considerable amount of research examining the pathways through which SES impacts health, it is important to note there can be multiple pathways through which each aspect of SES impacts health and the time span during which this impact manifests can also vary (Braveman & Gottlieb, 2014). Although identifying the mechanisms through which neighbourhood SES influences development of children with ASD can help develop appropriate policies and programs, this remains a challenge from a research method perspective. Complex, multifactorial causal pathways, which are hypothesized to link neighbourhood SES and health, can not be easily tested with

randomized controlled trials. However, even with lack of clarity regarding these mechanisms, providing customized early interventions based on the relationship between neighbourhood SES and specific areas of development in different provinces and territories can meaningfully support the health of children with ASD.

The findings of this study demonstrate that neighbourhood deprivation has an independent effect on development of children with ASD after controlling for individual demographic and family socioeconomic characteristics. However, considering that the positive relationship between neighbourhood deprivation and developmental vulnerability among children with this disorder was not observed in every province and territory for every area of development, it is possible there are protective factors in place to moderate the adverse impact of neighbourhood deprivation. These can include a variety of factors such as social capital, social support, self-esteem, and self-efficacy (Matthews, Gallo, & Taylor, 2010; Seeman, Epel, Gruenewald, Karlamangla, & McEwen, 2010; Uphoff, Pickett, Cabieses, Small, & Wright, 2013). Among these factors, social capital, which is defined as an attribute of society that represents the norms of reciprocity and trustworthiness that arise from social networks, is increasingly studied in relation to socioeconomic inequalities of health (Uphoff et al., 2013). Findings of a systematic review show that social capital may buffer the negative health effects of low SES and social capital has a stronger positive effect on health of those with a lower SES (Uphoff et al., 2013). In the context of early childhood development, there is some evidence on social factors that moderate the negative impact of low neighbourhood SES. For example, Xue et al. (2005) found that when resident involvement in local organizations and

collective efficacy is included in the model, relationship between neighbourhood deprivation and children's internalizing behaviour problems no longer remains significant. While it was not possible to examine similar moderators of the relationship between neighbourhood deprivation and development of children with ASD in this study, future research can explore these moderators to enhance our understanding of why low neighbourhood SES negatively impacts development of these children only in some provinces.

In addition to ecological factors such as neighbourhood SES, the age at which children receive their ASD diagnosis can itself be an important determinant of their developmental trajectory. As has been highlighted throughout this thesis, early diagnosis is crucial for facilitating access to early intervention services. Identifying factors associated with age of diagnosis is needed to develop strategies for lowering the age of diagnosis. Thus far, a variety of child, family, and community level characteristics have been identified as factors affecting age of diagnosis (Rosenberg, Landa, Law, Stuart, & Law, 2011). However, in our case study in Ontario, no child characteristics were associated with age of diagnosis. This emphasizes the importance of using context specific evidence to inform policies and programs as factors that have been consistently associated with age of diagnosis in other studies, such as residence in rural areas leading to delays in age of diagnosis, were not observed in this study (Rosenberg et al., 2011). In examining the relationship between different primary care provider characteristics with age at diagnosis, we hypothesized that age at diagnosis will differ according to primary care provider's membership in primary care models, as there is evidence indicating

membership in these models has implications for access to services (Singh, Dahrouge, & Green, 2019). We found the time to diagnosis was longer among children with paediatrician as a primary care provider compared to children with primary care provider who was in care models. Additionally, the age of diagnosis was lower among children with primary care provider with domestic medical training compared to children whose provider had foreign medical training. In this light, the need for ASD specific professional education programming, specifically focusing on providers with foreign training and paediatricians, is emphasized as this can help fill an important knowledge gap to help support earlier diagnosis of ASD.

### **3.2 Implications of Study Findings**

As it has been discussed throughout this chapter, findings of this thesis can help inform early intervention service delivery by focusing on areas of need in relation to spatial clusters of children with ASD in provinces and territories, the development of these children, as well as the impact of neighbourhood SES on their development. With increasing evidence suggesting interventions that begin at a young age predict significant developmental gains and an improved developmental trajectory, investing in early intervention services for children with ASD can generate significant return on investment throughout their lifespan as they grow older (Itzhak & Zachorbc, 2011; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). This is supported by findings of a cost-benefit analysis, which shows participation in Early Intensive Behavioural Intervention between the age of 2 years and school entry estimates cost savings that range from \$187,000 to \$203,000 per

child for ages 3–22 years, and from \$656,000 to \$1,082,000 per child for ages 3–55 years (Jacobson, Mulick, & Green, 1998).

Beyond informing the type and volume of early intervention services to be provided in different locations, findings of this thesis can also help inform a variety of policies and programs in areas including health, education, safety and security, and economic/social development to contribute meaningfully to the development of children with ASD. This can be done by focusing on the relationship between neighbourhood SES and development of these children. For example, in provinces where there is a positive relationship between neighbourhood deprivation and developmental vulnerability, investing in a social infrastructure that addresses this deprivation can help support the development of children with ASD. The extent of this investment can be determined by the proportions of low SES neighbourhoods in provinces and territories.

This thesis contributed to the literature by demonstrating that neighbourhood SES has a significant impact on development of children with ASD in some provinces in Canada, which can be used as a starting point to guide further research in this area. For example, in Ontario, British Columbia, Manitoba, and Newfoundland and Labrador, the human, social, and economic components included in the neighbourhood SES index can be studied individually to examine which components explain the most variance in the developmental vulnerability of children with this disorder, which could contribute to a more nuanced understanding of this relationship. Identifying components of neighbourhood SES that are most important for these children's development can help facilitate a more targeted approach in service planning in the future. However, even in the

provinces where higher neighbourhood SES was associated with lower developmental vulnerability, child, family, or community level characteristics that have been identified as potential moderators of this relationship in the literature can be tested in future studies to determine whether the independent effect of neighbourhood SES on development remains when relevant moderators are included in the statistical models. Considering the difficulty in designing methodologically rigorous studies to examine the pathways through which neighbourhood SES influences development, there is particular value in conducting qualitative studies in Nova Scotia, where higher neighbourhood SES was associated with higher developmental vulnerability. By gaining a better understanding of families, communities, and service infrastructure in higher SES neighbourhoods, such studies can help generate hypotheses regarding pathways between neighbourhood SES and development of children with ASD.

For Ontario, the findings of this thesis helped identify factors associated with the age of ASD diagnosis as well as determined the role of neighbourhood SES in affecting development of children with this disorder. The framework used in the Ontario case study can be used for other provinces and territories to identify factors associated with age of diagnosis in different regions. Not only will this help develop policies, programs, and interventions to reduce age of diagnosis in provinces where neighbourhood SES is associated with children's development, but it can also help expedite efforts to deliver necessary services to support their development at an earlier age.

## **Conclusion**

This study contributed to the literature by examining the health of kindergarten children with ASD in the context of neighbourhoods. The pan-Canadian approach used in this study can be tremendously valuable to policy makers as they work to refine the national ASD strategy. The neighbourhood specific prevalence and developmental health information of children living in different provinces will support the development of programs and services according to areas of need. Findings of this study can also be used as a starting point to not only enhance our understanding of the influence of neighbourhood SES on development of children with ASD, but also identify factors that influence their age of diagnosis across Canada.

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