

Age at Diagnosis of Autism Spectrum Disorders in Four Regions of Canada

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ABSTRACT

Objectives: Early diagnosis of autism spectrum disorders (“autism”) may lead to better treatment outcomes, reduces the stress parents experience when they do not understand the reasons for their child’s behaviour, and empowers parents to make choices such as seeking genetic counseling. We examined the age at which Canadian children are diagnosed with autism, and analyzed whether there are geographic or temporal variations or differences by sex or diagnostic subtype.

Methods: As part of an autism surveillance program, in 2002/2003 we began collecting information on children with autism in Manitoba, Southeastern Ontario, Prince Edward Island, and Newfoundland and Labrador. For the analysis presented in this paper, we included children identified for our surveillance program who were diagnosed between 1997 and 2005 (n=769).

Results: We found significant inter-regional differences in age at diagnosis, with Newfoundland and Labrador having the lowest median age at diagnosis (39.0 months) and Southeastern Ontario the highest (55.0 months). Diagnostic subtype was significantly associated with age at diagnosis in all regions. Southeastern Ontario was the only region where the overall age at diagnosis increased over time ($p=0.004$), although in Manitoba the age at which children were diagnosed with PDD-NOS also increased significantly over the study period ($p=0.021$).

Conclusions: Our findings demonstrate that there are geographic differences and other sources of variation in the age at which Canadian children are diagnosed with autism. Further study is warranted to understand the factors contributing to these differences. Such research would inform best practices for early detection and timely access to treatment.

Key words: Autism; autism spectrum disorders; early identification; age at diagnosis

La traduction du résumé se trouve à la fin de l'article.

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Autism spectrum disorders – which include autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger’s disorder¹ – are a group of neurodevelopmental disorders that are characterized by marked impairments in social functioning and communication, as well as repetitive patterns of behaviour or restricted interests. Early intervention programs, which aim to help children modify their behaviour and learn new skills, are a widely used treatment for autism spectrum disorders (hereinafter referred to as “autism”). Some studies have reported greater improvements when children enter these programs at a younger age,^{2,3} and a recent report from the Centers for Disease Control and Prevention states: “Given the benefit of early intervention, identification of an ASD [autism spectrum disorder] at earlier ages in the United States is essential to ensure that children receive optimal early intervention services.”⁴ Early diagnosis also helps to reduce the confusion and stress parents experience when they do not understand the reasons for their child’s behaviour,⁵ and empowers them to make choices such as seeking genetic counseling.

In many cases, autism can be diagnosed reliably between two and three years of age,⁶⁻⁹ although often children are not identified until they are older.¹⁰⁻¹⁴ Several studies have reported decreases in the age at which children are diagnosed with autism when comparing birth cohorts^{15,16} or year of diagnosis,¹⁷ while other studies have found an increase in age at diagnosis across birth cohorts (although not statistically significant),¹² or no clear trend over

time.¹⁸ Geographic differences have also been reported. For example, the median age at first autism diagnosis ranged from 49 months in Utah to 66 months in Alabama, based on surveillance data for children who were 8 years old in 2002.⁴

There is little information on the age at which Canadian children are first diagnosed with autism, apart from one study that used administrative data to estimate the prevalence of autism among children in Manitoba and Prince Edward Island (PEI) in 2002. In

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Table 1. Agencies in Manitoba, Southeastern Ontario, Prince Edward Island and Newfoundland and Labrador that Identify Children with an Autism Spectrum Disorder for the National Epidemiologic Database for the Study of Autism in Canada

Region	Agency	Population Served	Method of Data Collection	Year Data Collection Started
Manitoba	Children's Special Services, Manitoba Department of Family Services & Housing	All children under the age of 18, with the exception of children living on reserves	Agency staff review files and complete anonymized data collection forms for children under 18 years of age with an autism spectrum disorder	2002
Southeastern Ontario	Limestone District School Board	School-age children	Agencies provide the research team with the date of birth and sex of all children under 15 years of age with an autism spectrum disorder, and send information letters and consent forms to their parents or legal guardians. If a consent form is sent back to the study team, more detailed demographic and diagnostic information is collected by telephone interview with the parent or legal guardian.	2003
	Upper Canada District School Board	School-age children		
	Hastings & Prince Edward District School Board	School-age children		
	Algonquin & Lakeshore Catholic District School Board	School-age children		
	Catholic District School Board of Eastern Ontario	School-age children		
	Conseil des écoles publiques de l'Est de l'Ontario	School-age children		
	Conseil des écoles catholiques de langue française du Centre-Est	School-age children		
Prince Edward Island	Child Development Centre, Hôtel Dieu Hospital*	All children under 18 years of age living in Southeastern Ontario	Same as for Southeastern Ontario, except includes all children under 18 years of age with an autism spectrum disorder.	2002
	Pathways for Children & Youth, Autism Intervention Program	Children 2-5 years of age who have been diagnosed with autistic disorder or are considered to be on the severe end of the autism spectrum		
Newfoundland & Labrador	Department of Education	School-age children	Same as for Southeastern Ontario	2003
	Department of Health and Community Services, Early Intensive Intervention Services	Children 18-84 months of age with an autism spectrum disorder		

* Referral and assessment centre for children with suspected developmental problems.

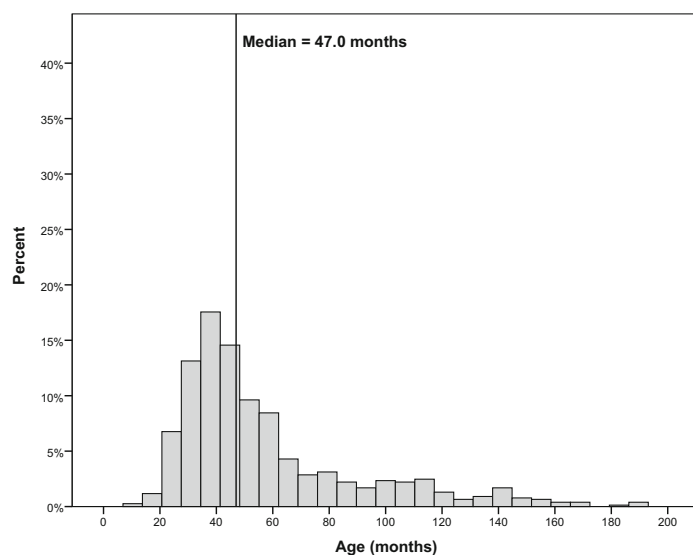
those provinces, the median age at diagnosis was 3.7 and 3.6 years, respectively.¹⁹ The objectives of the current analysis were to determine: 1) the age at which children in various regions of Canada are first diagnosed with autism; 2) whether geographic variations in age at diagnosis exist; and 3) whether there is a trend towards earlier diagnosis in more recent years. We also examined whether there are differences in age at diagnosis between boys and girls and across diagnostic subtypes.

METHODS

Data source and sample

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) was established in 2001. It functions as a surveillance program for diagnosed cases of autism among children in various regions of Canada. Because the delivery of health, social services and education differs across provinces, different protocols were adopted in the surveillance regions with the goal of achieving maximum case ascertainment in the most cost-effective manner possible (see Table 1). Ethics approval was obtained from the PEI Research Ethics Board, and from research ethics boards at the University of Manitoba, Queen's University, and Memorial University for ongoing surveillance in PEI, Manitoba, Southeastern Ontario, and Newfoundland and Labrador, respectively. NEDSAC contains the date of birth and sex of all children identified by participating agencies in the surveillance regions. Depending on the amount of information that is available in files (Manitoba), or whether the family consents

Figure 1. Age in months at which children living in Manitoba, Southeastern Ontario, Prince Edward Island, and Newfoundland and Labrador were first diagnosed with an autism spectrum disorder between 1997 and 2005, inclusive (n=769)



to provide more detailed information to the research team (Southeastern Ontario, PEI, Newfoundland and Labrador), the database also contains information on whether the child is adopted, number of siblings and number of siblings with

Figure 2. Age in months at which children living in Manitoba were first diagnosed with an autism spectrum disorder between 1997 and 2005, inclusive (n=505)

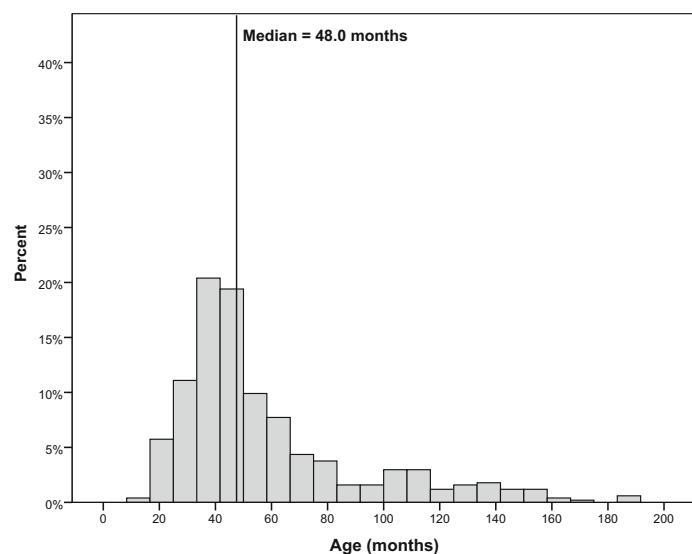
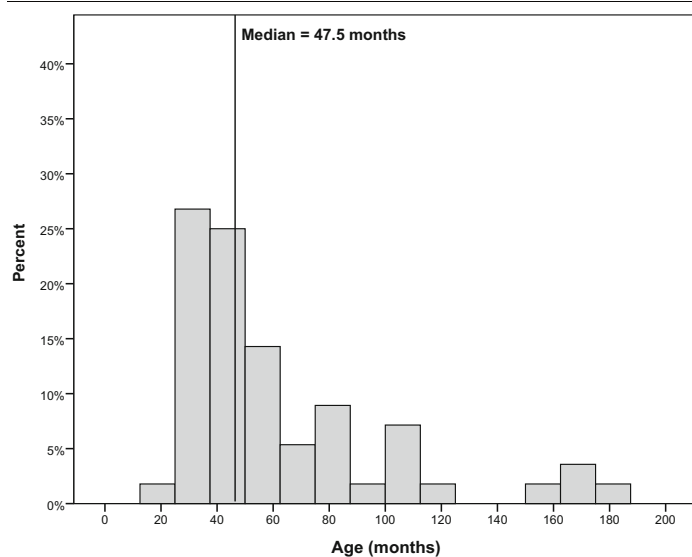


Figure 4. Age in months at which children living in Prince Edward Island were first diagnosed with an autism spectrum disorder between 1997 and 2005, inclusive (n=56)



autism, first three digits of the postal code of the child's current residence, birthplace, maternal and paternal age, ethno-cultural identity, diagnostic subtype, date of diagnosis, who made the diagnosis, and the tests that were used.

For the current analysis, we included children identified for NED-SAC from the time data collection began (2002 in Manitoba and PEI; 2003 in Southeastern Ontario and Newfoundland and Labrador) up until May 2007, who: 1) were first diagnosed with autistic disorder, PDD-NOS, Asperger's disorder, or a non-specific diagnosis of autism spectrum disorder between 1997 and 2005, inclusive, and whose month of diagnosis was known; and 2) were born in one of the surveillance regions and still living there in the year when diagnosed, or, if they were born elsewhere, diagnosed either in the same year they moved to the surveillance region or in a subsequent year.

Figure 3. Age in months at which children living in Southeastern Ontario were first diagnosed with an autism spectrum disorder between 1997 and 2005, inclusive (n=117)

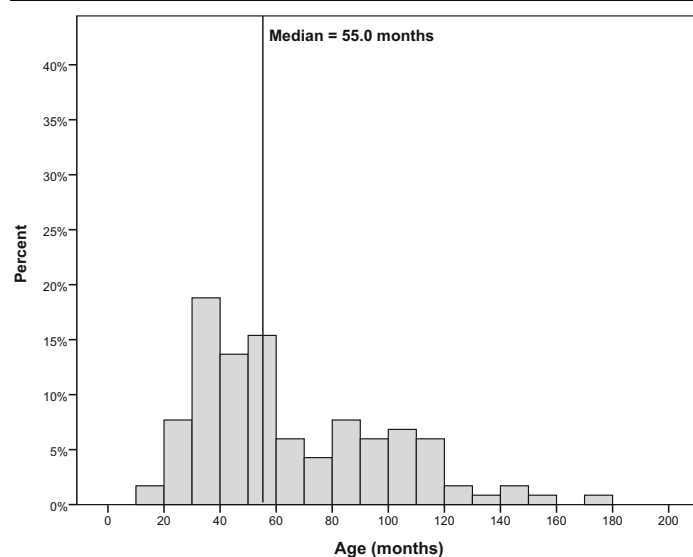
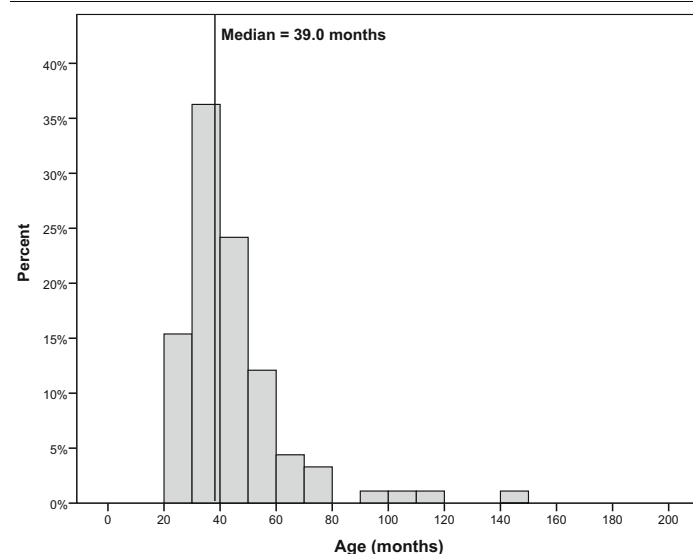


Figure 5. Age in months at which children living in Newfoundland and Labrador were first diagnosed with an autism spectrum disorder between 1997 and 2005, inclusive (n=91)



Analysis

Age at diagnosis is reported using medians and interquartile ranges due to the variable's skewed distribution (see Figures 1-5). We used SPSS 16.0.1 (SPSS Inc., Chicago, IL) and the Mann-Whitney or Kruskal-Wallis test to compare inter- and intra-regional findings for age at diagnosis by sex and diagnostic subtype (i.e., autistic disorder, PDD-NOS, Asperger's disorder, or general diagnosis on the autism spectrum ("ASD")), and inter-regional differences by three-year period in which the initial diagnosis was made (1997-1999, 2000-2002, 2003-2005). The Spearman's rank correlation was used to examine intra-regional trends by three-year period of initial diagnosis. For Manitoba – the only region with a sufficient sample size to conduct a stratified analysis – we also examined, for each diagnostic subtype, whether the age at diagnosis increased or decreased

Table 2. Median Age at First Diagnosis of an Autism Spectrum Disorder in Four Regions of Canada by Sex, Year of Initial Diagnosis and Diagnostic Subtype

	Manitoba		Southeastern Ontario		Prince Edward Island		Newfoundland & Labrador		p-value for Inter-regional Differences in Median Age at Diagnosis
	n (%)	Median Age, Months (IQ Range)	n (%)	Median Age, Months (IQ Range)	n (%)	Median Age, Months (IQ Range)	n (%)	Median Age, Months (IQ Range)	
Overall	505 (100.0)	48.0 (30.0)	117(100.0)	55.0 (51.5)	56 (100.0)	47.5 (41.0)	91 (100.0)	39.0 (17.0)	<0.001
Sex									
Boys	421 (83.4)	47.0 (29.5)	99 (84.6)	53.0 (48.0)	46 (82.1)	45.0 (42.0)	78 (85.7)	39.0 (17.3)	<0.001
Girls	84 (16.6)	50.0 (37.5)	18 (15.4)	64.0 (75.0)	10 (17.9)	50.5 (72.3)	13 (14.3)	41.0 (18.0)	0.067
<i>p-value for intra-regional differences in median age at diagnosis by sex</i>		0.217		0.255		0.171		0.905	
Year of initial diagnosis									
1997-1999	87 (17.2)	49.0 (24.0)	26 (22.2)	43.0 (24.5)	18 (32.1)	46.5 (35.8)	22 (24.2)	42.0 (17.3)	0.120
2000-2002	177 (35.0)	46.0 (30.0)	45 (38.5)	58.0 (55.5)	17 (30.4)	49.0 (46.5)	47 (51.6)	37.0 (24.0)	0.007
2003-2005	241 (47.7)	48.0 (35.5)	46 (39.3)	61.5 (53.5)	21 (37.5)	46.0 (64.5)	22 (24.2)	42.0 (14.5)	0.002
<i>p-value for intra-regional differences in median age at diagnosis by year of initial diagnosis</i>		0.562		0.004		0.205		0.745	
Diagnostic subtype									
Autistic disorder	183 (36.2)	42.0 (19.0)	24 (20.5)	34.0 (27.3)	11 (19.6)	44.0 (23.0)	27 (29.7)	40.0 (18.0)	0.206
PDD-NOS	69 (13.7)	77.0 (55.5)	25 (21.4)	59.0 (48.0)	12 (21.4)	50.0 (41.8)	19 (20.9)*	48.0 (33.0)†	0.001
Asperger's disorder	59 (11.7)	101.0 (65.0)	29 (24.8)	89.0 (43.0)	5 (8.9)	103.0 (40.5)	-	-	0.603
ASD	194 (38.4)	42.0 (20.3)	39 (33.3)	47.0 (20.0)	28 (50.0)	44.5 (24.5)	45 (49.5)	36.0 (13.5)	0.005
<i>p-value for intra-regional differences in median age at diagnosis by diagnostic subtype</i>		<0.001		<0.001		0.020		0.036	

Notes: The n denotes sample size used in the analysis, and does not reflect the total number of children diagnosed with an autism spectrum disorder for any of the categories listed. Percents are based on intra-regional totals. IQ = Interquartile, PDD-NOS = Pervasive developmental disorder, not otherwise specified, ASD = Autism spectrum disorder (non-specific diagnosis).

* Due to small numbers, the Asperger's disorder and PDD-NOS categories were grouped together.

† Values are for PDD-NOS only.

significantly by three-year period of initial diagnosis, using Spearman's rank correlation. All references to significance are based on two-tailed tests using an alpha of 0.05. We did not consider any adjustment of this alpha level for multiple testing because of the exploratory nature of the study.

RESULTS

Figures 1-5 illustrate the distribution of age at diagnosis for the combined sample and for each region. Table 2 reveals significant inter-regional differences in the median age at diagnosis overall ($p < 0.001$) and for boys ($p < 0.001$). Girls were diagnosed later than boys in all regions, although none of the differences was significant. The age at diagnosis differed significantly across regions for two time periods: 2000-2002, and 2003-2005. In Southeastern Ontario, it increased significantly over time ($p = 0.004$).

Significant inter-regional differences were observed for the median age at diagnosis of PDD-NOS and ASD. The age at which children were diagnosed with PDD-NOS was highest in Manitoba (77.0 months) and lowest in Newfoundland and Labrador (48.0 months). For the ASD category, Southeastern Ontario had the highest median age of diagnosis at 47.0 months, compared to 36.0 months for Newfoundland and Labrador. Significant differences in age at diagnosis for the diagnostic subtypes were found within all regions. Children with autistic disorder or ASD were diagnosed the earliest, followed by those with PDD-NOS. Children with Asperger's disorder were more likely to be diagnosed when they were older. For almost all the subgroup analyses, Newfoundland and Labrador had the lowest age at diagnosis. The only exception was for autistic disorder,

which was diagnosed earliest in Southeastern Ontario (34.0 months).

Table 3 shows that there was a significant increase over time in the median age at diagnosis of PDD-NOS in Manitoba ($p = 0.021$). An increase over time was also observed for Asperger's disorder in that province, but it was not significant.

DISCUSSION

The Senate Standing Committee on Social Affairs, Science and Technology, in its final report on the enquiry into funding autism treatment in Canada, noted there are waiting times for assessment and diagnosis, and parents frequently are "unable to access timely assessment and diagnosis of their children".²⁰ Although many cases of autism can be diagnosed reliably between two and three years of age,⁶⁻⁹ in three of the surveillance regions (Manitoba, Southeastern Ontario, PEI) about half the children were not diagnosed until four years of age or more.

Overall, Newfoundland and Labrador had the lowest median age at diagnosis. In that province, there is a "zero" waitlist policy for early intervention for preschool children diagnosed with autism. There may be more incentive for earlier diagnosis in regions with reduced waiting times for services. In contrast, Southeastern Ontario had the highest median age at diagnosis. One possible explanation for this is the large proportion of children identified with Asperger's disorder in that region (24.8%) compared to elsewhere (less than 12%). In all regions, consistent with findings from other studies,^{10,14,15,21} children with Asperger's disorder were diagnosed later than children with PDD-NOS or autistic disorder.

Table 3. Median Age at First Diagnosis of an Autism Spectrum Disorder in Manitoba by Year of Diagnosis and Diagnostic Subtype

Diagnostic Subtype	Year of Initial Diagnosis of an Autism Spectrum Disorder						p-value
	1997-1999		2000-2002		2003-2005		
	n	Median Age, Months (IQ Range)	n	Median Age, Months (IQ Range)	n	Median Age, Months (IQ Range)	
Autistic disorder	28	44.0 (19.5)	58	39.5 (15.5)	97	42.0 (20.0)	0.651
PDD-NOS	20	56.5 (47.8)	20	75.0 (61.5)	29	92.0 (51.5)	0.021
Asperger's disorder	5	70.0 (54.0)	23	74.0 (58.0)	31	108.0 (59.0)	0.080
ASD	34	43.5 (24.8)	76	43.0 (18.3)	84	41.0 (19.3)	0.391

Notes: The n denotes sample size used in the analysis, and does not reflect the total number of children diagnosed with an autism spectrum disorder for any of the categories listed.

IQ = Interquartile, PDD-NOS = Pervasive developmental disorder, not otherwise specified, ASD = Autism spectrum disorder (non-specific diagnosis).

Southeastern Ontario had the highest median age at diagnosis overall, yet children with autistic disorder were diagnosed earlier there than in any other region. Any child with autism who meets the age criteria is eligible for provincially funded intensive behavioural intervention programs in Manitoba, PEI, and Newfoundland and Labrador. In contrast, only children with autistic disorder or those on the severe end of the autism spectrum are eligible for the program in Ontario.²² One hypothesis for the anomalous finding for age at diagnosis of autistic disorder in Southeastern Ontario then is that assessment resources tend to be focused on the more severe cases, who may be eligible for provincially funded early intervention services.

Southeastern Ontario was also the one region where the age at diagnosis increased over time. In Manitoba, where the sample size was sufficient to conduct an analysis of age at diagnosis stratified by diagnostic subtype and year of initial diagnosis, temporal increases in age at diagnosis were observed for Asperger's disorder and for PDD-NOS. One possible explanation for these findings is that older, higher-functioning children who were not diagnosed in the past may be more likely to receive an autism diagnosis as awareness of the autism spectrum increases.

Several cautions and limitations of the methods need to be taken into account when interpreting the findings. Some investigators have compared birth cohorts when examining whether the age at which children are diagnosed with autism is decreasing.^{12,15,16} We chose to use calendar years instead, as children who were born in more recent years (e.g., late 1990s and early 2000s) may not yet have been diagnosed with autism, which would bias the results towards a younger age at diagnosis in later birth cohorts. Accordingly, it is not possible to directly compare our findings with those from studies that have examined age at diagnosis for birth cohorts. It is also important to note that the analysis presented in this paper did not include all children who were diagnosed with autism between 1997 and 2005 in the surveillance regions. NEDSAC does not contain information on children who moved from the surveillance regions before data collection began in 2002/2003. It is unlikely, however, that migration is related to age at diagnosis, and therefore the non-inclusion of these children would probably not affect the findings greatly. We also excluded from the analysis cases for whom the month or year of diagnosis were unknown, as well as cases whose residence in the surveillance regions during or prior to the year in which they were diagnosed could not be confirmed. To assess what effect the exclusion of these two groups of children might have on the findings, we examined the age and sex of children who were included and excluded from the analysis. No significant sex differences were detected between the groups. However, in all regions the group that was excluded from the analysis was significantly older than the group that was included. Since

current age of the child was significantly and inversely correlated with year of diagnosis in all regions, the children who were excluded from the analysis were more likely to have been diagnosed before 1997 and hence would not have met the inclusion criteria, or to have been diagnosed during the first three-year interval of the study period. Accordingly, the findings for 1997-1999 are where the greatest potential for bias exists.

While a discussion of diagnostic procedures over the study period is beyond the scope of this paper, it is probable that there were differences among regions as well as within each region over time in terms of the diagnostic criteria, types of professionals, and methods used to make the diagnosis. Regardless of how the diagnosis was made, however, early diagnosis is important for all the reasons mentioned in the introduction, and our findings suggest that children with autism are not being diagnosed at as young an age as the literature suggests they could be. Further study is warranted to understand the factors contributing to delays in diagnosis. Such research would inform best practices for early identification of autism and timely access to treatment and supports.

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RÉSUMÉ

Objectifs : Le diagnostic précoce des troubles du spectre autistique (« autisme ») peut mener à de meilleurs résultats de traitement, réduire le stress que vivent les parents lorsqu'ils ne sont pas en mesure de comprendre les raisons du comportement de leur enfant et habiliter les parents à prendre des décisions, comme recourir à la consultation

génétiq. Nous avons examiné l'âge auquel les enfants canadiens ont reçu un diagnostic d'autisme et avons analysé s'il y avait des variations géographiques ou temporelles ou encore des différences selon le sexe ou le sous-type de diagnostic.

Méthodes : En 2002-2003, nous avons entrepris, dans le cadre d'un programme de surveillance de l'autisme, la collecte de données sur des enfants atteints d'autisme au Manitoba, dans le sud-est de l'Ontario, à l'Île-du-Prince-Édouard et à Terre Neuve-et-Labrador. En ce qui concerne l'analyse présentée dans ce document, nous avons inclus les enfants, identifiés dans le cadre de notre programme de surveillance, ayant reçu un diagnostic entre 1997 et 2005 (n=769).

Résultats : Nous avons observé des différences importantes entre les régions sur le plan de l'âge au moment du diagnostic; Terre-Neuve-et-Labrador présentait l'âge moyen au moment du diagnostic le moins élevé (39,0 mois) et le sud-est de l'Ontario le plus élevé (55,0 mois). Le sous-type de diagnostic était fortement associé à l'âge au moment du diagnostic dans toutes les régions. Le sud-est de l'Ontario était la seule région où l'âge global au moment du diagnostic augmentait avec le temps (p=0,004), bien qu'au Manitoba, l'âge auquel les enfants reçoivent un diagnostic de TED-NS ait aussi augmenté considérablement au cours de la période à l'étude (p=0,021).

Conclusions : Nos conclusions démontrent qu'il existe des différences géographiques et d'autres sources de variation dans l'âge auquel les enfants canadiens reçoivent un diagnostic d'autisme. D'autres études s'avèrent nécessaires pour comprendre les facteurs qui contribuent à ces différences. Ces recherches permettraient de mieux documenter les meilleures pratiques concernant la détection précoce et l'accès rapide au traitement.

Mots clés : autisme; troubles du spectre autistique; détection précoce; âge au moment du diagnostic

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17-19 August 2009

Calgary, AB

Contact:

www.apha.ab.ca

40th Annual Conference of the Association of Canadian Ergonomists

Ergonomics - Think it. Live it.

14-17 September 2009

Quebec City, QC

Contact:

www.ace-ergocanada.ca

2009 Spirituality and Health Conference: Working Together For Optimal Health

24-26 September 2009

Calgary, AB

Contact:

http://www.ucalgary.ca/~psyc/tree/CPD_Spirituality.pdf

2nd McGill Conference on Global Food Security

Impacts of Global Financial Turmoil on Food Security

Faculty of Agricultural and Environmental Sciences

McGill University

5-7 October 2009

Montreal, QC

Contact:

E-mail: globalfoodsecurity@mcgill.ca

<http://www.mcgill.ca/globalfoodsecurity/>

16th Canadian Conference on International Health

Health Equity: Our Global Responsibility

Canadian Society for International Health

25-28 October 2009

Ottawa, ON

Contact: CSIH

Tel: 613-241-5785, ext. 326

E-mail: 2009ccih@csih.org

6th National Conference on Tobacco or Health

What Can We Learn 10 Years Later?

Organized by the Canadian Council for Tobacco Control

1-4 November 2009

Montréal, QC

Contact:

E-mail: conference@cctc.ca

www.ncth.ca

HealthAchieve 2009 – Inspiring Ideas and Innovation

Ontario Hospital Association

16-18 November 2009

Toronto, ON

See the latest in health care technology, listen to some of the most dynamic leaders in our industry and participate in sessions covering many of the issues facing health care today.

Contact:

www.ohahealthachieve.com

Forum 2009

Innovating for the Health of All: Innovation in Systems of Research for Health and Health Equity

Global Forum for Health Research

16-20 November 2009

Havana, Cuba

Contact:

www.globalforumhealth.org/shlinks/forum2009.php

Third International Chronic Disease Conference

Global Perspectives on Chronic Disease: Prevention & Management Conference 2009 – “Above and Beyond”

Alberta Health Services - Calgary

23-26 November 2009

Calgary, AB

Contact:

E-mail: cdm.conference@albertahealthservices.ca

www.cdmcalgary.ca

CPHA Centennial Conference/Conférence du centenaire de l'ACSP

13-16 June/juin 2010

Toronto, ON

Contact/contacter :

conference@cpha.ca