Age at First Diagnosis of an Autism Spectrum Disorder in Four Regions of Canada

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Autism Spectrum Disorders – Canadian American Research Consortium (ASD-CARC)

BACKGROUND

Early diagnosis of autism spectrum disorders (ASDs):
• May lead to better treatment outcomes.
• Reduces parental stress.
• Empowers parents to make choices such as seeking genetic counseling.
• Confers eligibility for services.

A reliable diagnosis can generally be made between 2 and 3 years of age (Stone et al., 1999), but children are often not diagnosed until they are older (Ouellette-Kuntz et al., 2009). There is little information on the age at which Canadian children are first diagnosed with ASDs. We therefore conducted two sets of analyses to look at different aspects of age at diagnosis among children identified with an ASD for a Canadian autism surveillance program (NEDSAC: the National Epidemiologic Database for the Study of Autism in Canada).
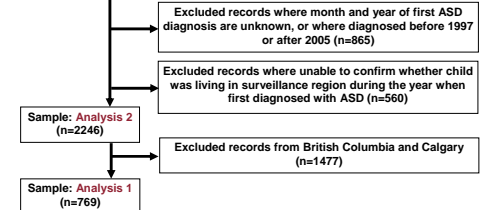
ABOUT THE NATIONAL EPIDEMIOLOGIC DATABASE FOR THE STUDY OF AUTISM IN CANADA (NEDSAC)

NEDSAC was established in 2001 as a surveillance program for ASDs in various areas of Canada. We have been collecting information on children diagnosed with an ASD in Prince Edward Island and Manitoba since 2002 and in Newfoundland & Labrador and Southeastern Ontario since 2003. Data were also collected from three major referral centres in Vancouver, British Columbia (2002-2007); and from the Developmental Clinic at Alberta Children's Hospital in Calgary, Alberta, as well as through various community sources in that city (2003-2006).

NEDSAC contains basic demographic and diagnostic information, including: date of birth, sex, whether the child is adopted, number of siblings and number of siblings with ASD, first three digits of the postal code of the child's last known residence in the surveillance region, birthplace, maternal and paternal ages, ethno-cultural identity, diagnostic subtype, date of diagnosis, who made the diagnosis, and the tests that were used.

SAMPLE

All records entered in NEDSAC from 2002/2003 up until May 2007 for children diagnosed with an ASD in British Columbia, Calgary, Manitoba, Southeastern Ontario, Prince Edward Island, and Newfoundland and Labrador (n=3671)

→ Excluded records where month and year of first ASD diagnosis are unknown, or where diagnosed before 1997 or after 2005 (n=865)

→ Excluded records where unable to confirm whether child was living in surveillance region during the year when first diagnosed with ASD (n=560)

Sample: Analysis 2 (n=2246)

→ Excluded records from British Columbia and Calgary (n=1477)

Sample: Analysis 1 (n=769)
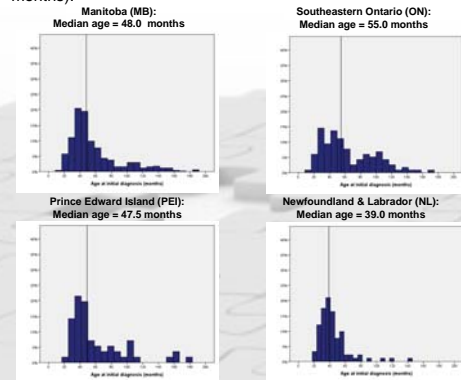
ANALYSIS 1*

OBJECTIVES
To determine:
• The age at which children in four regions of Canada (Manitoba, Southeastern Ontario, Prince Edward Island, and Newfoundland & Labrador) were first diagnosed with an ASD between 1997 and 2005.
• Whether the age at diagnosis is decreasing.

METHODS
• Mann-Whitney or Kruskal-Wallis test to compare age at diagnosis among regions, and by sex and diagnostic subtype within regions.
• Spearman's rank correlation to examine intra-regional trends by three-year period of initial diagnosis.
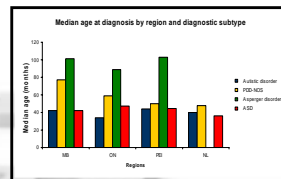
RESULTS
Geographic variations There was a significant difference in age at diagnosis among the four regions (p < .001). Newfoundland & Labrador had the lowest median age at diagnosis (39 months) and Southeastern Ontario the highest (55 months).
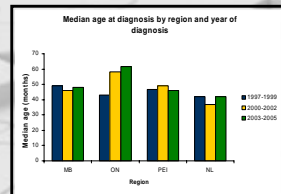

Manitoba (MB): Median age = 48.0 months
Southeastern Ontario (ON): Median age = 55.0 months
Prince Edward Island (PEI): Median age = 47.5 months
Newfoundland & Labrador (NL): Median age = 39.0 months

Temporal trends No significant decreases in age at diagnosis were found in any region. The age at diagnosis increased significantly over time in Southeastern Ontario (p=.004).

Median age at diagnosis by region and year of diagnosis

Sex differences Although in all regions girls tended to be diagnosed later than boys, the differences were not significant.

Median age at diagnosis by region and sex
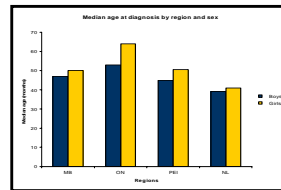
Diagnostic subtype In all regions, significant differences were observed in the age at diagnosis for different diagnostic subtypes.

Median age at diagnosis by region and diagnostic subtype

*More details on this analysis can be found in the July/August 2009 issue of the *Canadian Journal of Public Health*.

ANALYSIS 2

OBJECTIVE
To explore whether various factors are associated with the age at which children in six regions of Canada (British Columbia, Calgary, Manitoba, Southeastern Ontario, Prince Edward Island, and Newfoundland & Labrador) were first diagnosed with an ASD between 1997 and 2005.

METHODS
• Owing to small numbers for certain variables, we pooled the data for Calgary, Southeastern Ontario, Prince Edward Island, and Newfoundland & Labrador (=four combined regions).
• Missing data were imputed using PROC MI in SAS.
• Generalized linear regression models were fit to the data, specifying the log link function and gamma distribution.
• Generalized Estimation Equation (GEE) was used to estimate the model parameters.
• Two models were fit for each region: one using only records with complete data (=complete-case model) and one using all records with missing data imputed (=imputed model).

RESULTS
• R^2 values:
  • British Columbia: **.15 - .16**
  • Manitoba: **.35 - .38**
  • Four combined regions: **.34 - .37**

	British Columbia		Manitoba		Four Combined Regions	
	Exponentiated parameter estimate (95% CI)		Exponentiated parameter estimate (95% CI)		Exponentiated parameter estimate (95% CI)	
	Complete-case model (n=872)	Imputed model (n=1296)	Complete-case model (n=317)	Imputed model (n=505)	Complete-case model (n=356)	Imputed model (n=445)
Girls	1.02 (0.92-1.12)	1.01 (0.93-1.10)	1.10 (0.95-1.29)	1.07 (0.95-1.21)	1.14 (0.99-1.33)	1.12 (0.98-1.27)
Born outside Canada	**1.51 (1.30-1.74)**	**1.54 (1.35-1.77)**	1.27 (0.84-1.91)	1.26 (0.84-1.88)	1.17 (0.74-1.83)	**1.44 (1.00-2.08)**
Rural residence	1.09 (0.92-1.29)	1.08 (0.96-1.22)	1.06 (0.94-1.20)	1.09 (0.98-1.20)	1.01 (0.91-1.13)	1.01 (0.91-1.12)
Sibling(s) with ASD	0.92 (0.81-1.04)	**0.86 (0.77-0.97)**	0.93 (0.80-1.03)	0.98 (0.85-1.12)	0.89 (0.77-1.02)	0.88 (0.75-1.02)
Being adopted	0.99 (0.62-1.58)	1.19 (0.99-1.43)	1.04 (0.73-1.50)	1.05 (0.85-1.30)	1.06 (0.81-1.39)	1.34 (0.93-1.94)
Visible minority	**0.89 (0.83-0.96)**	**0.87 (0.81-0.94)**	0.94 (0.83-1.06)	0.93 (0.83-1.04)	0.98 (0.85-1.14)	1.00 (0.82-1.22)
Aboriginal	0.95 (0.79-1.15)	0.97 (0.80-1.19)	**1.19 (1.01-1.40)**	**1.16 (1.00-1.34)**	0.93 (0.76-1.15)	0.87 (0.66-1.16)
Middle tertile median household income	1.03 (0.95-1.13)	1.05 (0.98-1.13)	0.92 (0.82-1.04)	0.96 (0.88-1.06)	1.06 (0.95-1.18)	1.03 (0.93-1.14)
Upper tertile median household income	1.02 (0.94-1.11)	1.06 (0.99-1.13)	0.93 (0.82-1.06)	1.00 (0.90-1.11)	0.95 (0.83-1.08)	0.92 (0.83-1.04)
Diagnosed 2000-2002	1.04 (0.96-1.14)	**1.14 (1.06-1.23)**	0.93 (0.81-1.06)	0.97 (0.86-1.10)	**1.15 (1.03-1.29)**	1.11 (0.99-1.24)
Diagnosed 2003-2005	**1.33 (1.22-1.44)**	**1.37 (1.28-1.47)**	1.02 (0.90-1.17)	1.02 (0.91-1.15)	**1.22 (1.08-1.38)**	**1.21 (1.08-1.36)**
PDD-NOS	1.10 (0.99-1.22)	**1.15 (1.06-1.25)**	**1.63 (1.40-1.90)**	**1.70 (1.50-1.94)**	**1.26 (1.10-1.44)**	**1.20 (1.06-1.36)**
Asperger disorder	**1.68 (1.49-1.89)**	**1.64 (1.49-1.82)**	**2.04 (1.76-2.37)**	**2.09 (1.87-2.34)**	**2.12 (1.85-2.43)**	**1.91 (1.69-2.16)**
Autism spectrum disorder	0.95 (0.88-1.03)	0.95 (0.89-1.01)	1.02 (0.91-1.14)	1.01 (0.92-1.11)	1.06 (0.94-1.20)	0.99 (0.88-1.11)

CONCLUSIONS
• Many children with ASD in Canada are not being diagnosed at as young an age as the literature suggests they could be.
• It does not appear that children are being diagnosed earlier in more recent years, at least not during the period we examined.
• Very little of the variation in age at diagnosis was accounted for by the variables we looked at. There is a need to determine which factors are contributing to delays in diagnosis, so that measures can be implemented to ensure earlier detection and access to treatment and supports for children and their families.

REFERENCES

Ouellette-Kuntz HMJ, Coo H, Lam M, Yu CT, Breitenbach MM, Hennessey PE, et al. Age at first diagnosis of an autism spectrum disorder in four regions of Canada. *Can J Public Health* 2009;100(4).
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