ASD CARC

Autism Spectrum Disorders
Canadian-American Research Consortium

NATIONAL EPIDEMIOLOGIC DATABASE FOR THE STUDY OF AUTISM IN CANADA:

UPDATE

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ABOUT US

The Autism Spectrum Disorders Canadian-American Research Consortium (ASD-CARC) is a group of more than 60 researchers, clinicians, service providers and families formed in 2001. The Principal Investigator and Program Director of ASD-CARC is Jeanette Holden (professor, Departments of Psychiatry and Physiology, Queen's University in Kingston, Ontario). With funding from the Canadian Institutes of Health Research, the ASD-CARC is studying a number of areas in autism, including candidate genes, early detection, dysmorphology and epidemiology. A major component of the latter project is the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), which is led by Hélène Ouellette-Kuntz (associate professor, Departments of Community Health & Epidemiology and Psychiatry, Queen's University).

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DISCLAIMER

The findings and interpretations expressed herein are those of the authors, and do not necessarily reflect the opinions of the Canadian Institutes of Health Research, or of the agencies that are participating in this project.

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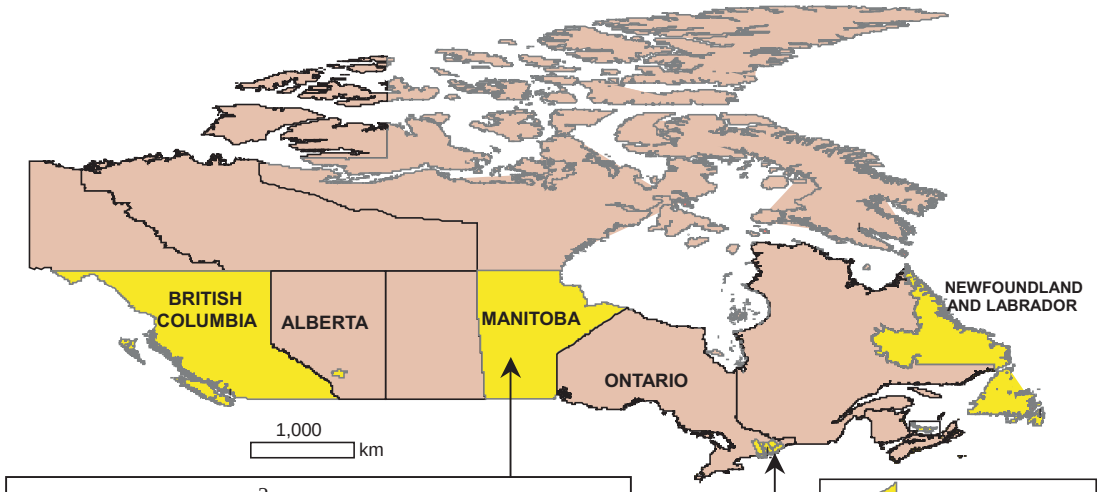
NATIONAL EPIDEMIOLOGIC DATABASE FOR THE STUDY OF AUTISM IN CANADA: UPDATE

The **National Epidemiologic Database for the Study of Autism in Canada (NEDSAC)** captures information on children under the age of 15 living in British Columbia, Calgary, Manitoba, Southeastern Ontario, Prince Edward Island (PEI) and Newfoundland & Labrador (shown on the map below in yellow) who have been diagnosed with an autism spectrum disorder (ASD). This family of disorders includes autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger disorder, Rett disorder and childhood disintegrative disorder. The findings in this report are based on 2002 data from Manitoba and PEI, and 2003 data from Southeastern Ontario.



Area: 647,797 km^2
Population density: 1.8 persons/km^2
Population under 15 years in 2002: 215,223*

Area: 19,808 km^2
Population density: 26.1 persons/km^2
Population under 15 years in 2003: 90,790

Area: 5660 km^2
Population density: 24.2 persons/km^2
Population under 15 years in 2002: 26,041

**Excludes children living on native reserves enumerated in 2001 census. These areas fall under federal jurisdiction and are not served by Children's Special Services, the agency used to identify children with autism spectrum disorders in Manitoba.*

Within these regions, the following agencies are participating in NEDSAC:

Manitoba	Children's Special Services, Manitoba Department of Family Services & Housing
PEI	PEI Department of Education PEI Department of Health & Social Services
Southeastern Ontario	Limestone District School Board Upper Canada District School Board Hastings & Prince Edward District School Board Algonquin & Lakeshore Catholic District School Board Catholic District School Board of Eastern Ontario Conseil des écoles publiques de l'Est de l'Ontario Conseil des écoles Catholiques de langue Française du Centre-Est Child Development Centre (Hotel Dieu Hospital) Pathways for Children & Youth

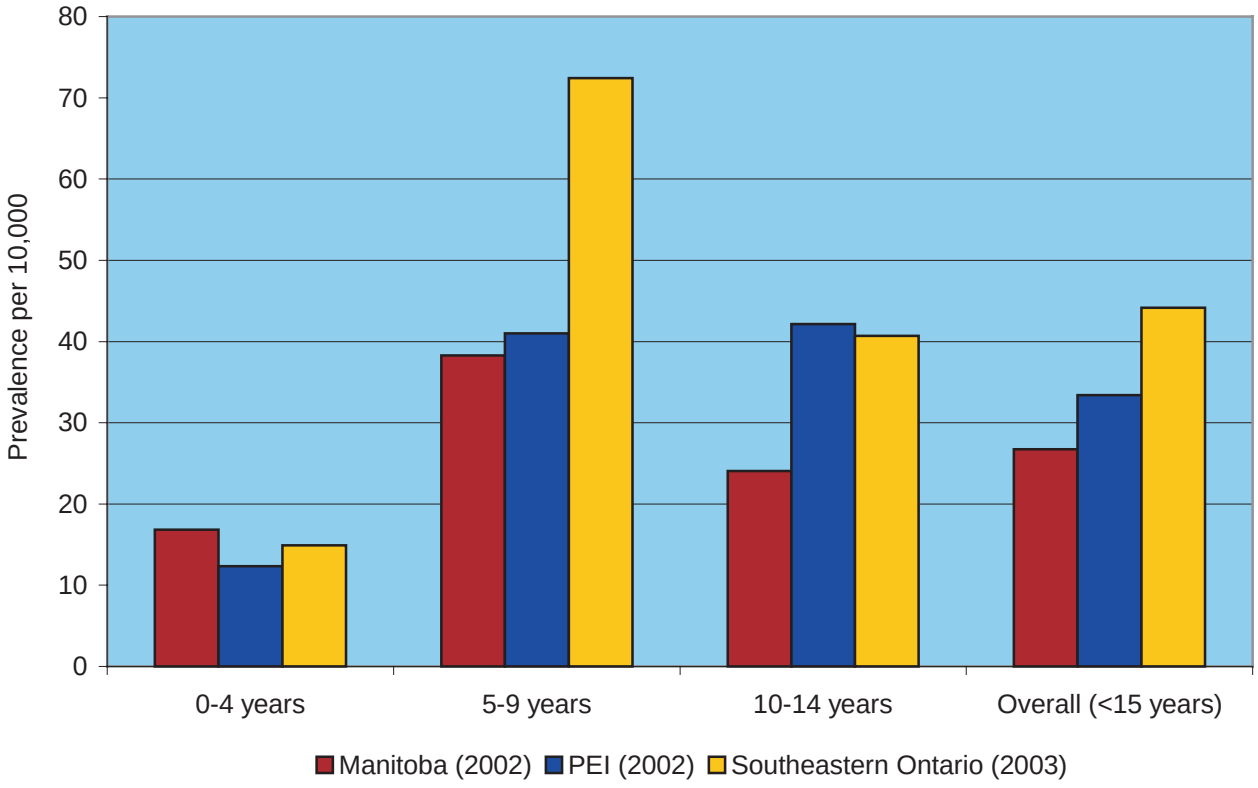
In Manitoba, non-identifying information (i.e. no names are included) is provided by Children's Special Services. In PEI and Southeastern Ontario, agencies mail families consent forms; families who return a signed form are contacted by telephone to collect information for NEDSAC. Agencies provide us with the age and sex of all children with an ASD; more detailed information, such as age at diagnosis, is only available in PEI and Southeastern Ontario for families who choose to participate. In PEI 74% of families consented to participate, compared to 40% in Southeastern Ontario.

To help you better interpret the findings, we have included a list of frequently asked questions at the end of this report. Our contact information is also given on the back cover if you would like more information about the contents of this report, or about the study in general.

I. Prevalence of ASDs

In 2002, there were 575 children under the age of 15 identified with an ASD in Manitoba, and 87 in PEI. In 2003, 399 children were identified with an ASD in Southeastern Ontario. The resulting prevalence of ASDs was 27, 33 and 44 per 10,000 in Manitoba, PEI and Southeastern Ontario, respectively (Fig.1). Southeastern Ontario's prevalence was higher than the other regions', due to its relatively high proportion of children 5 to 9 years of age with an ASD (72 per 10,000). We don't know why the prevalence of ASDs among this age group was so much higher in Southeastern Ontario than in Manitoba or PEI. However, a recent study done through an English-language school board in Montreal also detected a high prevalence of 67 per 10,000 school-age children.[1] We are currently seeking funding to confirm the diagnosis in a sample of NEDSAC cases and to conduct population screening, so that we can determine whether these differences in prevalence are real, or whether they are due to variations in the way children with ASD are identified in each region.

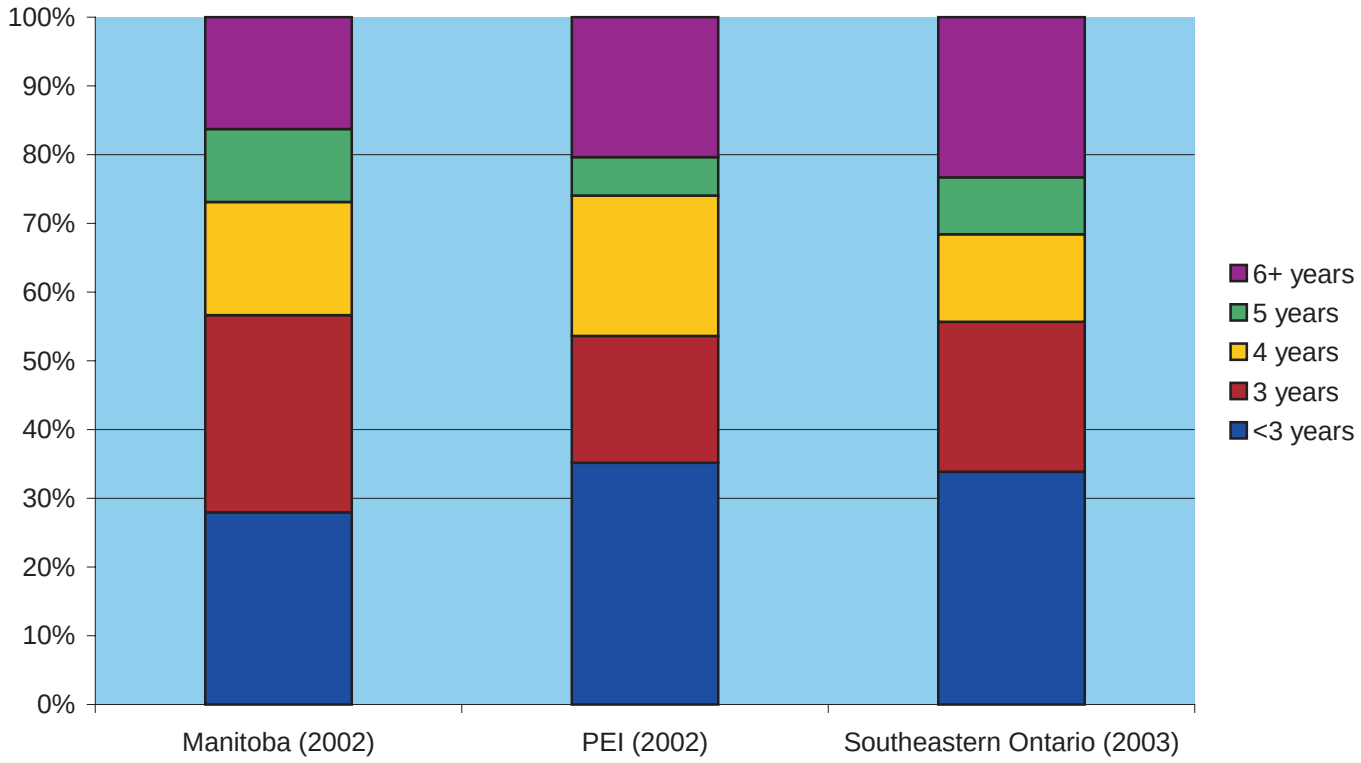
Fig.1 Prevalence of autism spectrum disorders



II. Age at which children are first diagnosed with an ASD

We know that clinicians are able to diagnose autistic disorder by age 3,[2] although diagnosis of the broader spectrum is not as reliable at this age.[3,4] In NEDSAC, information regarding age at first diagnosis was not available for all children diagnosed with an ASD. The chart below is based on data that was available for 443 children (77%) in Manitoba, 54 children (62%) in PEI, and 140 children (35%) in Southeastern Ontario. Therefore, this information may not accurately represent the age at diagnosis for all children with an ASD in those regions. Among those for whom information was available, more than half had been diagnosed before the age of 4 (Fig.2). However, a substantial proportion of children were not diagnosed until age 6 or over. It is important that children with an ASD be diagnosed as early as possible, as they can potentially benefit from early intervention.

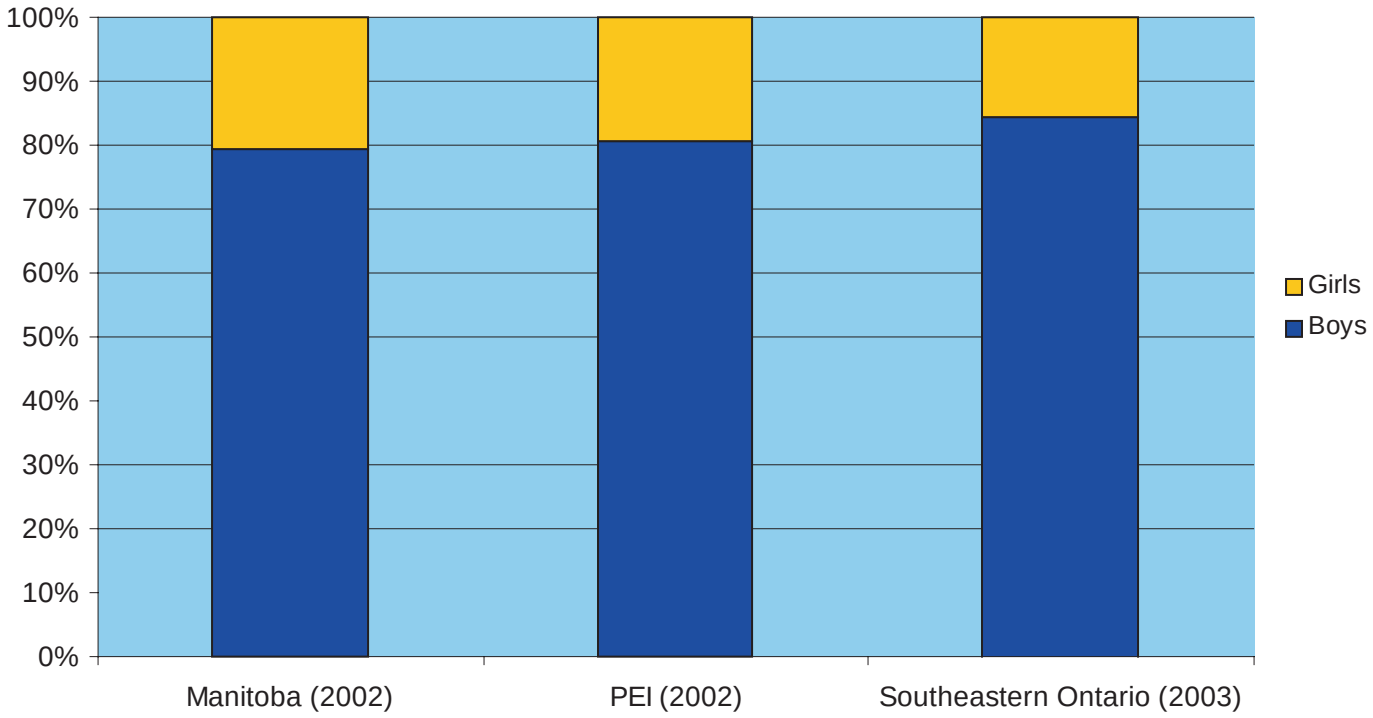
Fig.2 Age at first diagnosis of an autism spectrum disorder



III. Proportion of boys versus girls with an ASD

In all three regions, about 4 times more boys than girls were diagnosed with an ASD (Fig.3). This is similar to the 4:1 ratio reported among school children 5 to 11 years of age in Cambridgeshire, UK; however, that same study found that the boy:girl ratio among children educated in mainstream schools was 8:1, while the ratio among children attending special schools was 3:1.[5] While ASDs are more common among boys than girls, the size of the sex ratio is greatly affected by the methods that are used to identify children with an ASD.

Fig.3 Proportion of boys versus girls with an autism spectrum disorder



FREQUENTLY ASKED QUESTIONS

1. **What is prevalence and how is it different from incidence?**

   Prevalence is the proportion of individuals who have a condition at a specified point in time (in our study, the specified point in time was 2002 for Manitoba and PEI, and 2003 for Southeastern Ontario). Incidence is the number of new cases of a condition that develop in a population during a specified time period. A major difference between prevalence and incidence is that prevalence includes all existing cases, whereas incidence includes only new cases of a condition.

2. **In this study, were only the children of people who chose to participate counted, or were all children included?**

   All children under the age of 15 identified with an ASD were included in the calculation of prevalence.

3. **How can this be accurate when all those with an ASD older than 14 are not included?**

   Prevalence is generally reported for specific age groups, particularly as the occurrence of most conditions changes with age. The prevalence reported in this study relates only to children younger than 15.

4. **Why is the prevalence different in the three regions? What factors could influence this?**

   Different agencies are used to identify children with an ASD in the three regions. In Manitoba and PEI, only children receiving services are identified; assessment and diagnostic centres are also participating in Southeastern Ontario, which may partially account for the greater proportion of children who were identified with an ASD in that region. We need to do further studies before we can say with greater certainty why the reported prevalence differs from place to place.

5. **Since the rate reported by Bryson[6] in 1988 was 10 per 10,000, can we assume that rates are increasing?**

   No, we cannot make this assumption, as there were a number of major differences between our study and the one done by Bryson and colleagues. First, they studied children 6-14 years of age who were living in one part of Nova Scotia in 1985. Second, children with "autistic syndrome" as defined in the Bryson study (which may not include the full spectrum of children included in our prevalence estimates) were identified in a very different manner from the methods used in our study.

   To accurately determine whether prevalence is increasing, the same geographic region(s) should be monitored over a number of years using the same method(s) to identify children with an ASD. In addition, other factors that may affect prevalence, such as a changing average age at diagnosis, should be monitored. Over time, we should have a better idea as to whether the occurrence of ASDs is increasing in a given region of Canada.

6. **In Figure 1, the prevalence for 0-4 year olds is lower than for older children. What does this mean?**

   There are very few children younger than 3 who have been diagnosed with an ASD. This results in a lower prevalence among the 0-4 year age group.

7. **How long will the prevalence rate be monitored through your study?**

   Current funding for the project ends in December 2005. We are applying for additional research funding to continue monitoring the prevalence of ASDs in different regions of Canada.

8. **When will the next report be available?**

   Our next report should be available in early 2006. At that time, we hope to have more information on all six regions where we are monitoring the prevalence of ASDs.

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We would like to thank everyone who is participating in NEDSAC. Without your help, this research would not be possible. We will post more results on our website at www.AutismResearch.ca as they become available.

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