

NEDSAC

**Summary of Interim Findings from the
National Epidemiologic Database for the
Study of Autism in Canada
(NEDSAC)**

February 2008



ABOUT US

The National Epidemiologic Database for the Study of Autism in Canada (**NEDSAC**) was established in 2001 with funding from the Canadian Institutes of Health Research (CIHR) Interdisciplinary Health Research Team Program, as part of the Autism Spectrum Disorders–Canadian-American Research Consortium (grant #RT-43820, J.J.A. Holden, Queen’s University). Directed by H el ene Ouellette-Kuntz (Associate Professor in the Departments of Community Health & Epidemiology and Psychiatry at Queen’s University), NEDSAC received an additional five years of funding from CIHR in 2006 (grant #79556). We are continuing to collect data on children identified with an autism spectrum disorder (ASD) in various regions of Canada, as well as confirming the diagnosis in a sample of children whose information is entered in NEDSAC. We are also evaluating how well several parent and teacher questionnaires differentiate children with ASDs from those with other developmental disorders. Current NEDSAC team members include:

Coordinating Centre (Queen’s University, Kingston, Ontario): H. Ouellette-Kuntz, Director; H. Coo, Coordinator; H. Brown, Research Assistant; R. Goldberg, Research Assistant; J.J.A. Holden, Co-Investigator

British Columbia: M.E.S. Lewis, Regional Director; P. Carrion, Regional Coordinator

Alberta: D. Dewey, Regional Co-Director; F. Bernier, Regional Co-Director; D. Busic, Regional Coordinator

Manitoba: C.T. Yu, Regional Director; Q. Senkow, Regional Coordinator

Prince Edward Island: M. Breitenbach, Regional Co-Director; S.K. Henry, Regional Co-Director

Newfoundland and Labrador: P. Hennessey, Regional Co-Director; L. Crews, Regional Co-Director

ACKNOWLEDGEMENTS

We gratefully acknowledge the families and agencies in each region who have and who continue to provide information for NEDSAC. A full listing of agencies and partners can be viewed on our website at www.seocura.org/nedsac.html, or by going to www.autismresearch.com, clicking on the “Research Projects” tab and then the “Epidemiology” link. We would also like to thank Eleanor Chornoboy, Director, Interdepartmental Initiatives, Government of Manitoba for her support; Children’s Special Services, Department of Family Services and Housing in Manitoba for their assistance in data collection; Andrea Noonan and Robert Gauthier, who were NEDSAC Regional Co-Directors in PEI and Newfoundland and Labrador, respectively, during the period when the data in this report were collected; and Autism Calgary Association, Society for Treatment of Autism, Developmental Clinic at the Alberta Children’s Hospital, and Dr. Jean Fran ois Lemay at the Alberta Children’s Hospital for their ongoing support and assistance.

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.



The **National Epidemiologic Database for the Study of Autism in Canada (NEDSAC; www.seocura.org/nedsac.html)** was established in 2001 as a way to monitor, on an ongoing basis, the number of children with an autism spectrum disorder (ASD) living in Manitoba, Southeastern Ontario, Prince Edward Island (PEI) and Newfoundland and Labrador. In these regions, as well as in British Columbia and Calgary, we collect information about children with an ASD, including date of birth, sex, number of siblings, number of siblings who have an ASD, mother's and father's ages when the child was born, and ethno-cultural identity. In addition, we collect information about the types of professionals who made the diagnosis, the tests that were used, and the date the diagnosis was made. ASDs fall under the diagnostic category of pervasive developmental disorders, and include autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's disorder. Rett's disorder and childhood disintegrative disorder are also pervasive developmental disorders, but these conditions are rare. In this report, the term ASDs refers to all five of the pervasive developmental disorders.

This report describes the annual prevalence of ASDs among children 2 to 14 years of age in Manitoba, Southeastern Ontario, PEI, and Newfoundland and Labrador. The prevalence was calculated by dividing the number of children with an ASD living in a particular region at any time during a given calendar year by Statistics Canada estimates of the number of 2- to 14-year olds living in that region as of July 1. Because the method of data collection differed for each region, it is more valid to make comparisons within rather than across regions. The report also provides a brief summary of the number of boys compared to girls with an ASD, the age when the diagnosis was initially made, and the breakdown of specific ASD diagnoses for the six regions shown in green on the map below.



Manitoba

Participating Agencies

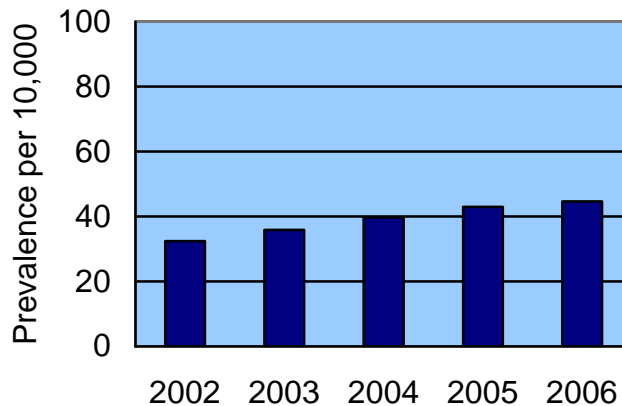
Children's Special Services, Manitoba Department of Family Services & Housing

Data Collection

Anonymized information is provided by Children's Special Services. Data collection began in 2002.

Prevalence¹

In Manitoba, the estimated prevalence of children with an ASD excludes children living on native reserves. These areas fall under federal jurisdiction and are not served by Children's Special Services, the agency used to identify children with ASDs in Manitoba. The on-reserve population was subtracted from the denominator when we calculated the prevalence.

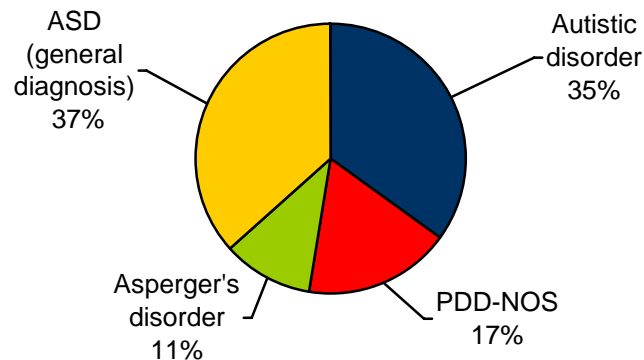


Boy to Girl Ratio² 4.1 to 1.0

Age at Diagnosis^{2,3}

The median age at diagnosis in Manitoba was 47 months (46 months for boys and 49 months for girls), and 27% were diagnosed at or before age 3.

Diagnosis²



¹ We have published a paper on the 2002 prevalence of ASDs in Manitoba and PEI (Ouellette-Kuntz *et al.*, 2006). Refer to page 9 for a full citation.

² Based on children included in prevalence for any year from 2002-2006 (n=1009) and ³for whom information was available in the child's file.

Southeastern Ontario

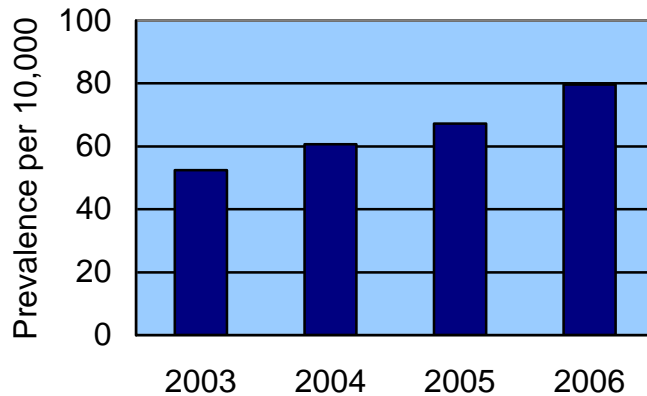
Participating Agencies

Hastings & Prince Edward District School Board; Algonquin & Lakeshore Catholic District School Board; Limestone District School Board; Upper Canada 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

Data Collection

In Southeastern Ontario, agencies provide us with the age and sex of all children with an ASD, and mail parents or legal guardians a consent form. Those who return a signed consent are contacted by telephone to collect more detailed information for NEDSAC. Accordingly, characteristics such as age at diagnosis are only available for families who choose to participate (34.1%). Data collection in Southeastern Ontario began in 2003.

Prevalence

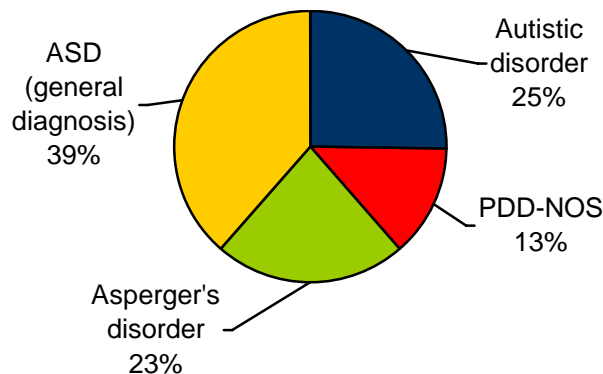


Boy to Girl Ratio¹ 4.8 to 1.0

Age at Diagnosis^{1,2}

The median age at diagnosis in Southeastern Ontario was 49.5 months (47 months for boys and 64 months for girls), and 6% were diagnosed at or before age 3.

Diagnosis^{1,2}



¹ Based on children included in prevalence for any year from 2003-2006 (n=744) and ²whose families agreed to be contacted to collect more detailed information for NEDSAC.

Prince Edward Island (PEI)

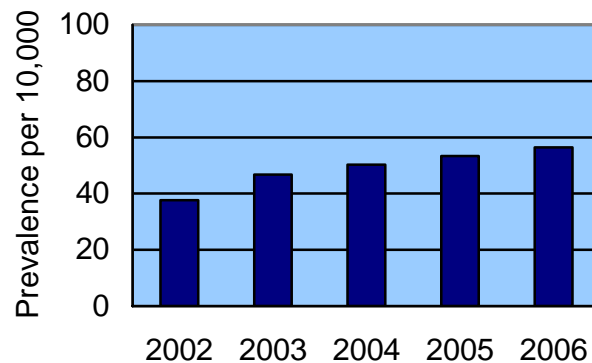
Participating Agencies

Department of Education; Department of Social Services and Seniors

Data Collection

In PEI, the departments listed above provide us with the age and sex of all children with an ASD, and mail parents or legal guardians a consent form. Those who return a signed form are contacted by telephone to collect more detailed information for NEDSAC. Therefore, characteristics such as age at diagnosis are only available for families who choose to participate (59.4%). Data collection in PEI began in 2002.

Prevalence¹

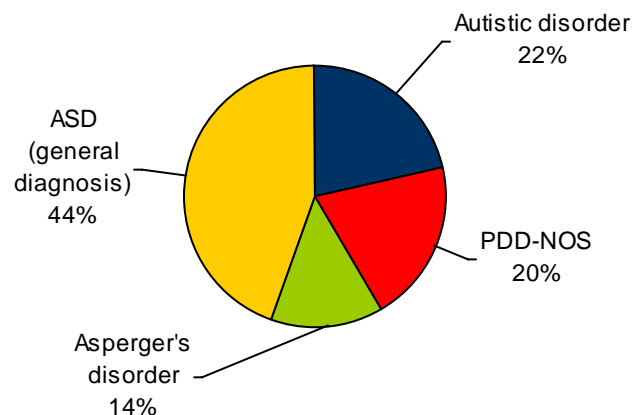


Boy to Girl Ratio² 5.5 to 1.0

Age at Diagnosis^{2,3}

The median age at diagnosis was 45.5 months (45 months for boys and 50 months for girls), and 14% were diagnosed at or before age 3.

Diagnosis^{2,3}



¹ We have published a paper on the 2002 prevalence of ASDs in Manitoba and PEI (Ouellette-Kuntz *et al.*, 2006). Refer to page 9 for a full citation.

² Based on children included in prevalence for any year from 2002-2006 (n=155) and ³whose families agreed to be contacted to collect more detailed information for NEDSAC.

Newfoundland & Labrador

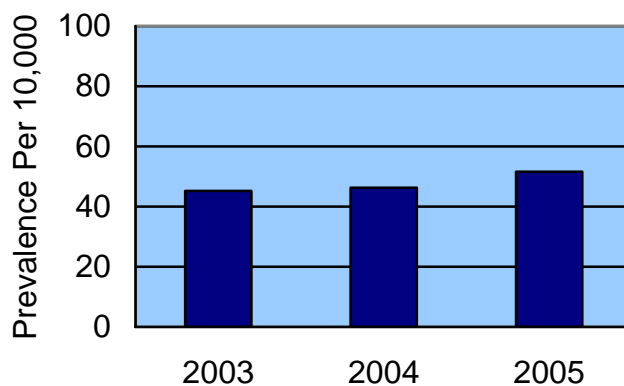
Participating Agencies

Department of Education; Department of Health and Community Services

Data Collection

In Newfoundland & Labrador, the departments listed above provide us with the age and sex of all children with an ASD, and mail parents or legal guardians a consent form. Those who return a signed form are contacted by telephone to collect more detailed information for NEDSAC. Accordingly, characteristics such as age at diagnosis are only available for families who choose to participate (41.6%). Data collection began in 2003.

Prevalence¹

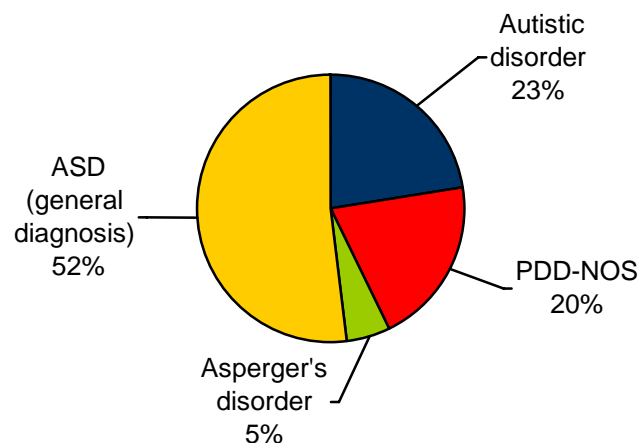


Boy to Girl Ratio² 4.5 to 1.0

Age at Diagnosis^{2,3}

The median age at diagnosis was 40 months (39 months for boys and 41.5 months for girls), and 12% were diagnosed at or before age 3.

Diagnosis^{2,3}



¹ Data for 2006 were not available at the time this report was prepared.

² Based on children included in prevalence for any year from 2003-2005 (n=416) and ³whose families agreed to be contacted to collect more detailed information for NEDSAC.

British Columbia (BC)

Participating Agencies

Provincial Autism Resource Centre at Sunny Hill Health Centre for Children; Departments of Psychiatry and Medical Genetics at the University of British Columbia; Children and Women's Health Centre of British Columbia

Data Collection

In BC, data collection began in 2002. Anonymized information is provided by the above agencies. Because the numbers provided reflect only those individuals referred to the diagnostic programs of the BC Provincial Health Services Authority, the findings presented below may not represent all children with an ASD living in BC.

In separate studies, we used data obtained through Edudata Canada and the BC Ministry of Education to examine the prevalence of autistic disorder in the BC school system (Coo *et al.*, 2007; Ouellette-Kuntz *et al.*, 2007; refer to page 9 for full citations).

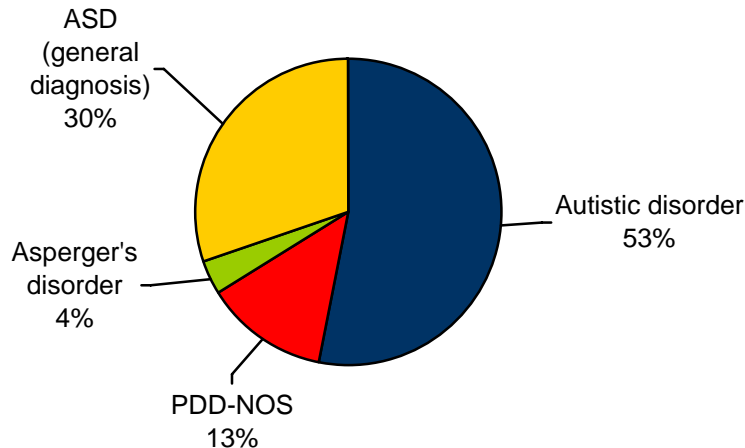
Boy to Girl Ratio¹ 4.4 to 1.0

Age at Diagnosis

^{1,2}

The median age at diagnosis was 55 months (55 months for boys and 52 months for girls), and 17% were diagnosed at or before age 3.

Diagnosis

¹

¹ Based on all records included in the BC portion of NEDSAC (n=2075) and ²for whom information was available in the child's file.

Calgary

Participating Agencies

Autism Calgary Association; Developmental Clinic at Alberta Children's Hospital; Society for Treatment of Autism; Renfrew Educational Services

Data Collection

In Calgary, data collection began in 2003. Anonymized information is provided by the above agencies. The participating agencies do not provide coverage of the entire population, and therefore the findings presented below may not represent all children with an ASD in Calgary.

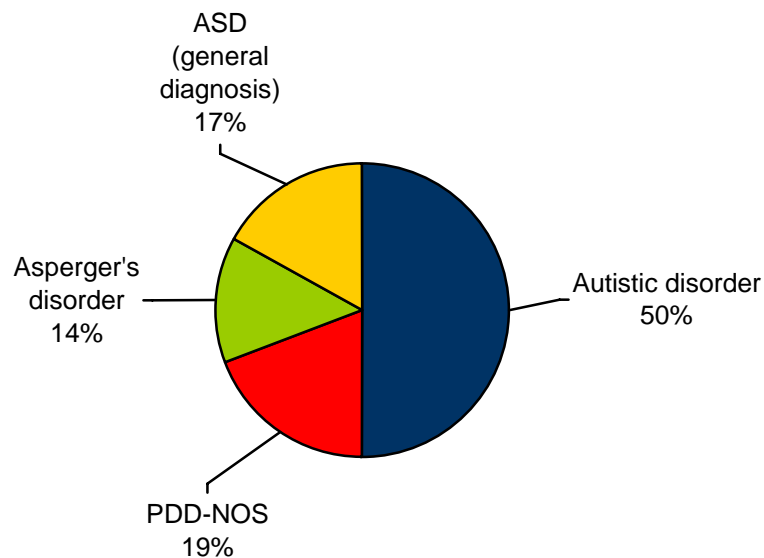
Boy to Girl Ratio¹ 4.6 to 1.0

Age at Diagnosis

^{1,2}

In Calgary, the median age at diagnosis was 46 months (46 months for boys and girls), and 20% were diagnosed at or before age 3.

Diagnosis

¹

¹ Based on all records included in the Calgary portion of NEDSAC (n=502) and ²for whom information was available in the child's file.

Discussion

NEDSAC was established as a surveillance program for ASDs. Health Canada states: "...key challenges facing those affected by ASD and their families include: the complexity of the condition; a lack of consensus and evidence regarding terminology, prevalence, treatments, and interventions; and difficulties in accessing effective and affordable care" (Health Canada, 2007). Surveillance can be used to build a profile of those who are affected by ASDs, and to assess the impact of this group of disorders on the health and education sectors in order to better plan the allocation of resources (Newschaffer & Curran, 2003; Rice *et al.*, 2004).

Recognizing the importance of ASD surveillance, the Centers for Disease Control and Prevention (CDC) in the United States has set up a surveillance system known as the Autism and Developmental Disabilities Monitoring (ADDM) Network. Information is abstracted from health and education records to monitor the occurrence and characteristics of ASDs among 8 year olds in 14 sites across the US (CDC, 2007).

In a recent report, the findings of the ADDM Network bear many similarities to those presented in our report. For example:

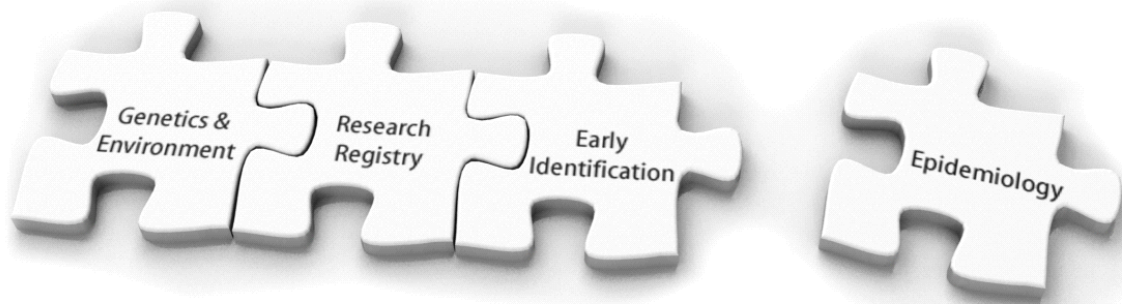
- They found considerable variation in prevalence across the 14 sites, ranging from 33 per 10,000 in Alabama to 106 per 10,000 children in New Jersey. We also have considerable variability in observed prevalence among our surveillance regions and across all years examined in this report, from 33 to 80 per 10,000. This variability is likely due to inter-regional differences in data collection protocols, and highlights the need to collect data from multiple sources in order to maximize the identification of children with an ASD.
- The ADDM Network reported a highly skewed sex ratio for ASDs, with anywhere from 3.4 to 6.5 more boys affected than girls. While we did not find this amount of variation in the boy-to-girl ratio, the number of boys with an ASD is at least four times higher than the number of girls in all NEDSAC regions.
- In the US, the median age at diagnosis ranged from 49 months in Utah to 66 months in Alabama. We also found inter-regional differences in the age at diagnosis. One possible explanation for this is the difference in the proportion of children identified with Asperger's disorder across regions, since it is generally diagnosed later than other ASDs (Mandell *et al.*, 2005). We also found that many Canadian children with ASDs are not diagnosed until well past the age of 3 years. It is important to monitor age at diagnosis to ensure that children are being identified as early as possible, to avoid delays in accessing potentially beneficial therapies.

Even though it is, at this stage, inadvisable to compare prevalence across the different NEDSAC regions due to variations in our data collection protocols, it is possible to comment on patterns within a particular region. In the four areas where it was reported, the prevalence increased each year. We will continue to monitor prevalence to determine if this trend continues. If it does, it will be important to examine the implications both for provision of services, and in terms of potential risk factors.

As we continue to build NEDSAC, our hope is that we will gain a better understanding of this group of disorders, and how they affect the Canadian population.

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We would like to thank everyone who is participating in NEDSAC. Without your help, this research would not be possible. If you are interested in reading more about our work, our website can be found at www.seocura.org/nedsac.html. A list of our peer-reviewed papers can be found by clicking on the Publications link. For more information on the work of the Autism Spectrum Disorders – Canadian-American Research Consortium (ASD-CARC), visit www.AutismResearch.com.

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