NEDSAC

Findings from the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC): Changes in the Prevalence of Autism Spectrum Disorders in Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario

March 2012

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 Hélène 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).

Over the years, many individuals have been involved in NEDSAC. For a complete list of current team members, visit our website at www.nedsac.ca. The findings presented in this report were prepared by the following NEDSAC team members: Hélène Ouellette-Kuntz, Director; Helen Coo, Coordinator; and Deb Gorski, Research Assistant. We would like to thank Julia Gordon for her assistance with proofreading and formatting.

ACKNOWLEDGEMENTS

We gratefully acknowledge the families and agencies in each region that provided information for NEDSAC. A full listing of those agencies can be viewed on our website at www.nedsac.ca. We would also like to thank Andrea Noonan (Prince Edward Island), Lori Crews and Robert Gauthier (both Newfoundland and Labrador), who served as NEDSAC Regional Co-Directors when some of the data used in this report were collected.

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 participated in this project.

CIHR IRSC
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Queen's University

The **National Epidemiologic Database for the Study of Autism in Canada** (**NEDSAC**; **www.nedsac.ca**) was established as a way to monitor the number of children diagnosed with an autism spectrum disorder (ASD) in different regions of Canada. ASDs currently include autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger disorder. The terms "ASDs" and "autism" are used interchangeably in this report.

In this report, we present the findings from NEDSAC surveillance programs in Newfoundland and Labrador (2003–2008), Prince Edward Island (2003–2010) and Southeastern Ontario[a] (2003–2010). Children with an ASD were identified to NEDSAC through agencies that provide services to this population (these agencies are described later in the report). Basic information (date of birth and sex) on all children identified was provided to the research team; the agencies then mailed information letters and consent forms to the parents or legal guardians (referred to in the rest of this report simply as parents) of those children. If a consent form was returned, a member of the research team conducted a telephone interview with the parent to collect more detailed information on the child, including the number of brothers or sisters and whether any of them has also been diagnosed with an ASD, where the child was born, his or her ethnocultural identity, information about the diagnosis, and the mother's and father's date of birth.

[a] Includes the six counties of Hastings, Prince Edward, Lennox & Addington, Frontenac, Lanark, Leeds & Grenville

SOME TERMS USED IN THIS REPORT

Cases: Individuals with the condition of interest. In this report, "cases" refers to children 2 to 14 years of age diagnosed with an ASD.

Diagnostic subtype: Autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), Asperger disorder, or general diagnosis of autism spectrum disorder.

Incidence: The number of new cases that develop in a population over a given period of time. Incidence is generally used to determine whether the risk for a condition is changing—that is, whether the actual occurrence of the condition is increasing or decreasing. Sometimes it may look like a condition is affecting more (or fewer) people, but that could be due to other factors. For example, some of the observed increase in the proportion of individuals with ASDs may be due to better awareness of these conditions among parents and professionals, which may mean that a child with an ASD is now more likely to be diagnosed than he or she would have been 15 or 20 years ago.

Nonrespondents: Parents who did not return a consent form to the research team. More detailed information about the child and his or her diagnosis was not obtained in these instances.

Prevalence: The proportion of the population that has the condition at a given point in time. See the shaded box below.

Prevalence of autism spectrum disorders in a given year = *a/b*

a (numerator) = The number of children aged 2–14 years with an ASD who lived in the region at any time during the year. Our numerator data is provided by agencies in the three regions that identify cases to NEDSAC. These agencies are listed in the *Findings* section for each region beginning on p.6.

b (denominator) = The total number of children aged 2–14 years who lived in the region in that year. We use estimates of the population from Statistics Canada for our denominators.

Prevalence year: This is a term that relates to the way children with ASDs are identified to NEDSAC. In each region, agencies provide us with the date of birth, sex, and prevalence year of all cases they serve. The prevalence year is the year in which the child was first known to have lived in the region and to have an ASD diagnosis. It does not necessarily correspond to the year in which the child was first diagnosed with an ASD. For example, if a child started school in 2005 and had a diagnosis at that time, the school would likely report the prevalence year as 2005. However, the child may actually have been diagnosed before he or she started school.

Respondents: Parents who returned a consent form to the research team, which meant more detailed information about the child and his or her diagnosis was entered into NEDSAC.

Study period: Here, the range of years for which ASD prevalence is reported. For Newfoundland and Labrador, the study period is 2003 to 2008 (cases in that province were last identified to NEDSAC in 2009, but the counts are incomplete for that year). For Prince Edward Island and Southeastern Ontario, the study period is 2003 to 2010.

HOW THIS REPORT IS ORGANIZED

This report describes the annual prevalence of ASDs among children 2 to 14 years of age in Newfoundland and Labrador, Prince Edward Island and Southeastern Ontario. Since the method of data collection differs slightly for each region, it is more valid to make comparisons within rather than across regions. Accordingly, the findings are presented in separate sections for each region, beginning on page 6. Each section starts with two graphs that show the annual prevalence during the study period by i) age group (2–4 years, 5–9 years, 10–14 years) and ii) sex.

To help you interpret these findings, we then address the following questions.

1. **How accurate are our prevalence estimates?**

   It is important to note that NEDSAC collects information on children diagnosed with an ASD only; the prevalence estimates do not include individuals who may have an ASD but have not been diagnosed. To determine how accurate our findings are in terms of estimating the prevalence of children *diagnosed* with an ASD, we have to first answer the following questions:

   a. **How likely is it that we are identifying all children 2 to 14 years of age diagnosed with an ASD**?

      To answer this, we describe the agencies that identified cases to NEDSAC in each region, and which groups of children with autism may not have been captured through those agencies.

   b. **Are all those identified really cases?**

      Because autism can be diagnosed by different professionals (pediatricians, psychologists, psychiatrists, etc.) with different levels of training, it is important to confirm that individuals whose information is entered in NEDSAC meet research criteria for having an ASD. To examine this, we conducted a study on a sample of children whose information was entered in NEDSAC. The study examined what percent of those children met the criteria for "Autism" on the Autism Diagnostic Interview–Revised[1] (a parent interview that asks about the child's social and communication skills and repetitive behaviours) or the criteria for "Autism" or "ASD'" on the Autism Diagnostic Observation Schedule–Generic[2] (an observational assessment of the child). The findings are included in this report.

   c. **Did the methods we used to identify cases affect the accuracy of our prevalence estimates?**

      When we first started collecting data for NEDSAC, participating agencies identified all cases they currently served. Once annually in the following years, we asked them to provide us with a list of new cases, and to inform us whether any previously identified cases had died, moved from the region, had their diagnosis of ASD removed, or were no longer with the agency for reasons other than those already mentioned. There are two potential sources of error with this process. First, as already noted under *Some Terms Used in this Report* (p.2), the prevalence year provided by the agency does not always correspond to the year of diagnosis. For respondents, we ask parents when their child was diagnosed. If an agency listed the prevalence year as 2004 but the parents informed us the child was born in the region and diagnosed with an ASD in 2003, we would include that child in the annual prevalence estimates from 2003 onwards. We do not have the date of diagnosis for the children of nonrespondents, however, and include them in prevalence estimates starting in the prevalence year provided by the agency. It is therefore possible that some cases were not included as early as they

should have been in the annual estimates. We cannot know for certain how often this occurred; however, we can estimate the frequency based on the proportion of respondents who reported that their child lived in the region and had an ASD diagnosis prior to the prevalence year provided by the agency.

Inaccuracies in our estimates could also occur if agencies did not inform us that a case moved from the region, had his or her diagnosis of ASD removed, or died. We need this information in order to remove the child from the numerator used to calculate prevalence from that date forward. For example, if a child moved from the region in 2005 but the agency did not report this to us, we would continue to include that child in prevalence estimates for the rest of the study period even though he or she no longer lived in the region. This is only a potential problem among nonrespondents. Again, we cannot determine how frequently it occurred in that group. However, we can estimate the potential extent of the problem by comparing what respondents told us with the information provided by the agencies.

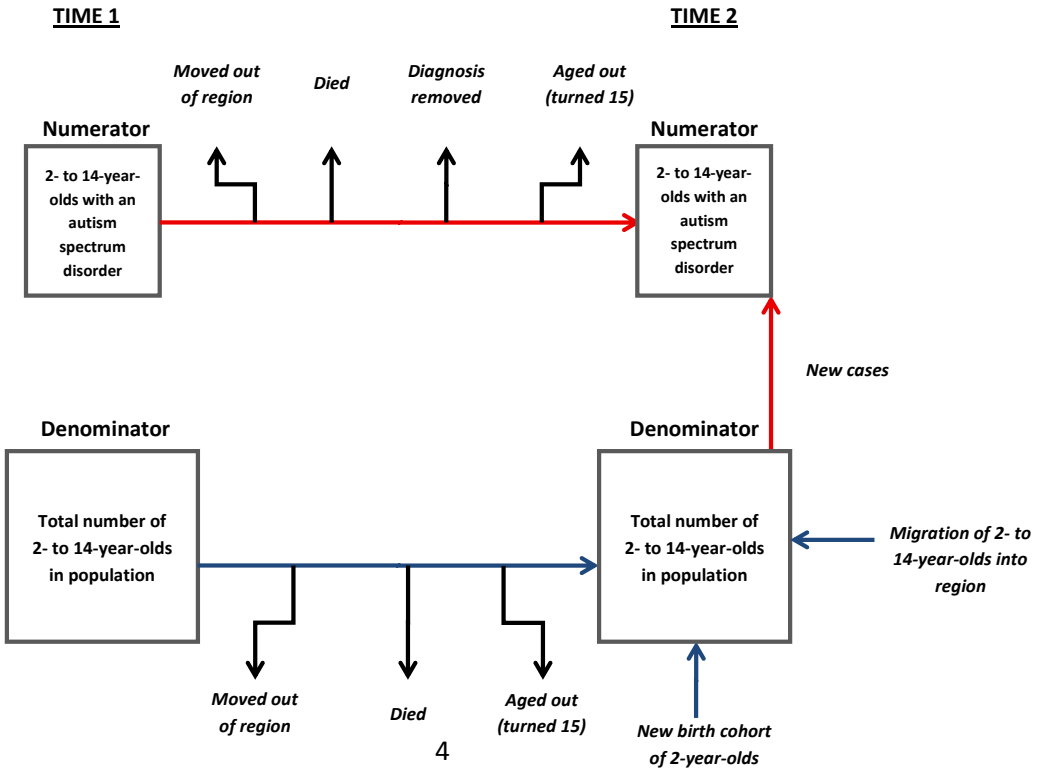
2. Did the prevalence change significantly over the study period?

Even if the prevalence was higher in 2008 or 2010 than in 2003, it does not necessarily mean the increase was statistically significant. The prevalence figures we and others report are associated with a certain amount of variation. Statistical tests take this variation into account when making comparisons between two or more measurements. We note whether any regional differences in prevalence can be considered significant in the *Findings* sections.

3. What factors might have contributed to changes in prevalence?

There are many things to consider when trying to understand changes in the prevalence of ASDs. The following figure illustrates some of the factors that have an impact on the numerators and denominators used to calculate prevalence from one time point to another.

Figure 1. Factors that contribute to changes over time in the numerators and denominators used to calculate the prevalence of autism spectrum disorders



While all these factors will affect the prevalence, not all of them are related to changes in the occurrence (incidence) of ASDs. For example, a net increase in the numerator could result from more cases moving into the region than leaving it during the study period. However, that increase would not be due to any change in risk.

The information in NEDSAC allows us to assess whether the following factors are likely to have had an impact on changes in prevalence over the study period.

a. Diagnostic changes

If children with ASDs tend to be diagnosed earlier over the study period, it could make it appear as though the prevalence is increasing. Assessing the impact of changes in age at diagnosis on changes in prevalence is difficult, particularly when examining a range of ages across a number of years.[3] Accordingly, in this report we only consider how differences in the age at diagnosis between the first and second halves of the study period could affect the observed prevalence among the younger age group (2- to 4-year-olds), where the greatest impact would be expected. It is also worth noting that most children with ASDs are likely to have been diagnosed by age 10, so any changes in age at diagnosis would have a minimal impact on changes in prevalence among the 10–14 year age group.

Greater detection of children with milder forms of ASD—PDD-NOS, Asperger disorder or "autism spectrum disorder"—has been suggested as one factor contributing to observed increases in prevalence.[4] In this report, we compare the distribution of diagnostic subtypes for newly diagnosed cases during the first and second halves of the study period in Newfoundland and Labrador and Southeastern Ontario. (This analysis was not done for Prince Edward Island; in that province, we were informed that children in recent years have been given a general diagnosis of "autism spectrum disorder" only.)

b. Changes in the numerator used to calculate prevalence during the study period because cases moved into the region after 2003, or moved from the region, had their diagnosis removed, or died before their 15th birthday

These factors could cause changes in prevalence that are unrelated to any change in the occurrence of ASDs.

A brief note regarding removal of the ASD diagnosis: in a national survey of parents in the United States, 38% of children who were reported as having been diagnosed with ASD no longer had that diagnosis.[5] The authors of the study gave several possible explanations for this finding: 1) the difficulties of diagnosing ASDs at a very young age, so that children "lose" the diagnosis as they get older and no longer display the symptoms of autism; 2) an ASD may have been suspected at some point but a formal diagnosis was never given; 3) an ASD diagnosis may have been given to children with learning disabilities or other conditions to provide the family access to certain services; or 4) parents may have reported their child no longer has an ASD if he or she was not receiving autism-specific services.

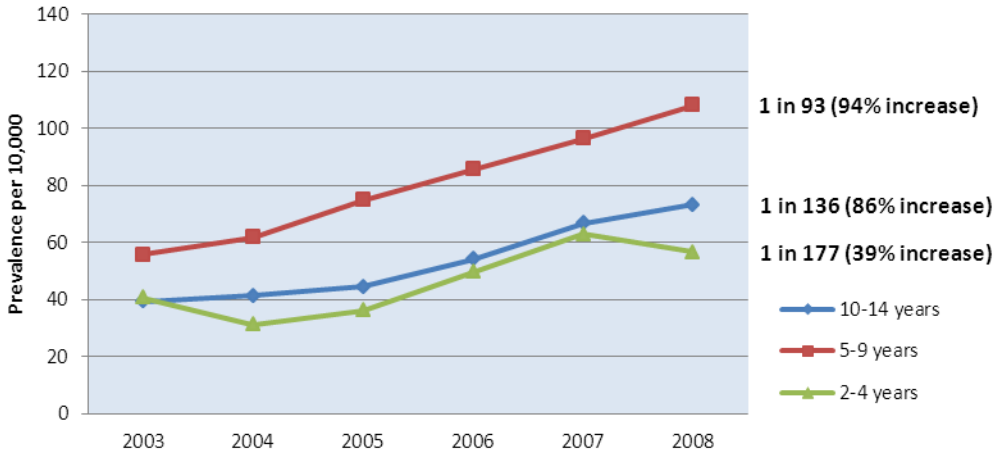
c. The methods used to identify cases

The methods used to identify cases to NEDSAC could also affect the measured prevalence. See item 1c (p.3) for a detailed explanation of those methods.

Findings for Newfoundland and Labrador

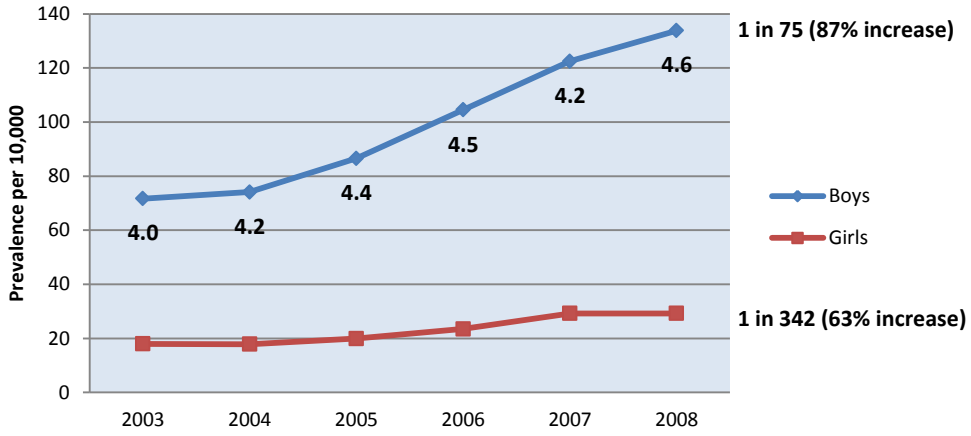
In Newfoundland and Labrador, 700 children with an ASD were identified in at least one year between 2003 and 2008. Consent forms were returned for 229 of these children (32.7%). Prevalence estimates for each year by a) age group and b) sex are shown in the graphs below (Table 4 on p.21 gives the numbers used to calculate these estimates). The y-axis represents the prevalence per 10,000 children. To convert "x per 10,000" to "1 in x" figures (which are shown in bold for the final data point in each series), divide 10,000 by the prevalence. (For example, the prevalence per 10,000 children 5–9 years of age in 2008 was 108.1. If you divide 10,000 by 108.1 (=93), the prevalence can also be reported as 1 in 93 for this age group.) The overall prevalence (for children 2–14 years of age) is not shown in the following graph, but in 2003 it was 45.6 per 10,000 compared to 83.0 per 10,000 in 2008.

Figure 2. Estimated prevalence of autism spectrum disorders in Newfoundland and Labrador by age group (2003–2008)[a]



Note: The numbers on the right show the prevalence expressed in terms of "1 in x children" for 2008. The information in brackets shows the percent change in prevalence between the first and last years of the study period.

Figure 3. Estimated prevalence of autism spectrum disorders in Newfoundland and Labrador by sex, and boy:girl ratio (2003–2008)[a]



Note: The values below each data point indicate the number of boys with an autism spectrum disorder for every girl. The numbers on the right show the prevalence expressed in terms of "1 in x children" for 2008. The

[a] See page 21 for the number of cases of ASD identified and the population estimates used to calculate the prevalence.

information in brackets shows the percent change in prevalence between the first and last years of the study period.

1. How accurate are our prevalence estimates for Newfoundland and Labrador?

a. How likely is it that we are identifying all children 2 to 14 years of age diagnosed with an ASD?

In Newfoundland and Labrador, data for NEDSAC were provided by a) the Department of Health and Community Services, which identified children receiving provincially funded intensive behavioural intervention services (all children with autism are eligible for these services up to school entry) and those diagnosed with an ASD by one of the diagnostic teams associated with the four Regional Health Authorities serving the province; and b) the Department of Education. Children who were home-schooled or attended private schools may not have been captured unless they were identified through the Department of Health and Community Services. In 2009, public school principals in Newfoundland and Labrador sent a letter to the parents of school-age children with an ASD describing the NEDSAC project and the data that are collected. Parents were informed they could contact the Department of Education to opt out of having any information on their child provided to the research team. Five parents opted out and their children's information was not included in NEDSAC.

b. Are all those identified really cases?

Fourteen children from Newfoundland and Labrador were assessed using the Autism Diagnostic Interview or the Autism Diagnostic Observation Schedule. All met the criteria for "Autism".

c. Did the methods we used to identify cases affect the accuracy of our prevalence estimates?

For 32 children of respondents (14.0%), the prevalence year provided by the agency was later than the year parents reported that the child was first living in Newfoundland and Labrador and had an ASD diagnosis. This means that some children of nonrespondents may not have been included as early as they should have been in the annual prevalence estimates.

There were no instances where the participating agencies failed to inform us that a child moved, had his or her diagnosis removed, or died (based on information provided by respondents). If we assume the situation was the same for nonrespondents, then it is unlikely cases were mistakenly included in prevalence estimates for any of the study years.

2. Did the prevalence change over the study period?

When we did statistical tests to compare the prevalence in 2008 with the prevalence in 2003, we found a statistically significant increase for two age groups (5–9 and 10–14 years). Although the change in prevalence was not technically significant for the 2–4 year age group, it was very close (a p-value of less than .05 is considered significant; the p-value for the 2–4 year age group was .05).

3. What factors might have contributed to the observed increases in prevalence?

a. Diagnostic changes

Table 1 and Figure 4 below, which are based on information provided by respondents for children newly diagnosed during the study period, indicate that children with ASDs

tended to be diagnosed at a later age in the second half of the study period compared to the first half (based on a comparison of the median age at diagnosis and the proportion of new diagnoses that were made before a child's fifth birthday). As noted previously, an *earlier* age at diagnosis in the latter part of the study period might result in an increase in prevalence among the 2–4 year age group. Accordingly, the data do not support age at diagnosis as an explanation for the increase in prevalence in the younger age group. (It is important to note, however, that the table and figure only include information provided by respondents, and do not necessarily reflect the diagnostic situation among the children of nonrespondents.)

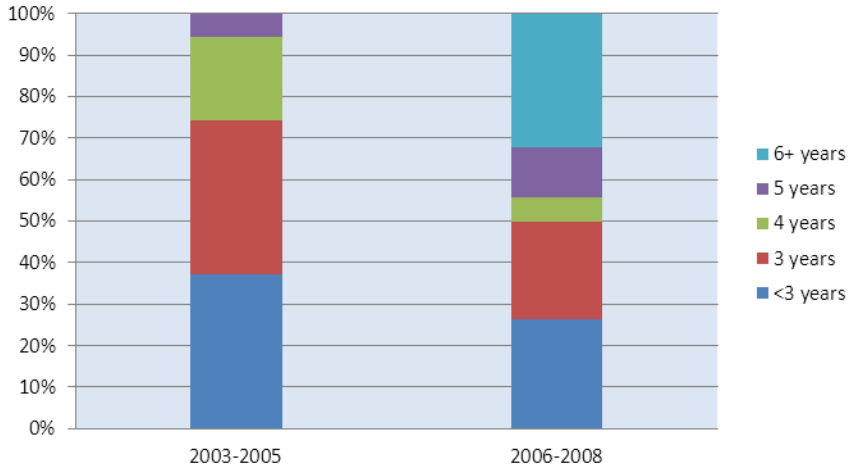
Table 1. Age at diagnosis (based on information provided by respondents who were diagnosed in Newfoundland and Labrador between 2003 and 2008 and where an age at initial diagnosis could be calculated; n=69)

	Median, months (range)
2003–2008	41.0 (13–143)
2003–2005	39.0 (13–66)
2006–2008	47.5 (24–143)*
Boys, 2003–2008	43.0 (13–126)
Girls, 2003–2008	34.0 (18–143)†

**There was a statistically significant difference in the age at diagnosis when comparing children diagnosed in 2003–2005 and 2006–2008.*

†There was no statistically significant difference in the age at diagnosis for boys and girls. Note that the small number of girls in this analysis (n=10) may have made it difficult to detect a statistical effect.

Figure 4. Proportion of children diagnosed with an autism spectrum disorder at different ages during first and second halves of study period (based on information provided by respondents and where an age at initial diagnosis could be calculated; n=69)

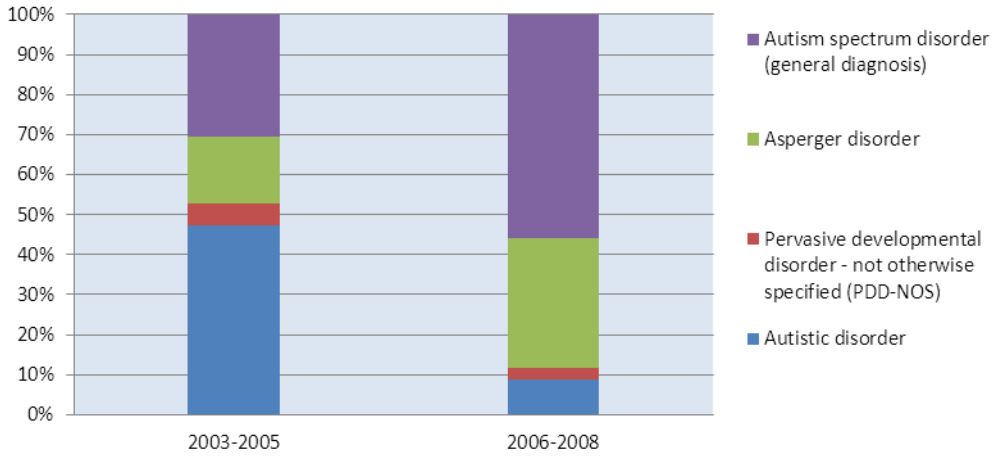


There was a statistically significant difference in the proportion of diagnoses made before age 5 when comparing children diagnosed in 2003–2005 and 2006–2008.

Figure 5 below, which is based on information from respondents for children newly diagnosed during the study period, provides some support for the hypothesis that greater detection of milder cases over the study period contributed to increases in

prevalence: the proportion of "autistic disorder" diagnoses (the most severe form of ASD) decreased significantly in the second half of the study period.

Figure 5. Diagnostic subtypes for cases diagnosed in Newfoundland and Labrador during first and second halves of study period (based on information provided by respondents who were diagnosed in Newfoundland and Labrador between 2003 and 2008; n=70)



There was a statistically significant difference in the proportion of autistic disorder diagnoses when comparing children diagnosed in 2003–2005 and 2006–2008.

b. Changes in the numerator used to calculate prevalence during the study period because cases moved into the region after 2003, or moved from the region, had their diagnosis removed, or died before their 15th birthday

Among the 229 children of respondents, 3 (1.3%) moved to Newfoundland and Labrador after 2003. If we assume the situation was the same for the children of nonrespondents, another 6 individuals may have been added to the numerators used to calculate prevalence in 2004 or later because of migration into the province. In contrast, of the 700 cases identified overall, 12 were removed from the numerator before 2008 because the family moved from the province, the diagnosis of ASD was removed, or the child died. Thus, over the study period we estimate that 9 individuals were added to the numerator after 2003 and 12 were removed from the numerator before 2008 for reasons that cannot be attributed to changes in incidence. If our assumptions are correct, these factors would have caused a net decrease in the numerators used to calculate prevalence.

c. The methods used to identify cases

For 32 children of respondents (14.0%), the prevalence year provided by the agency was later than the year parents reported that the child was first living in the region and had an ASD diagnosis. We could include these children in the numerator for the correct year because of the information provided by parents. However, if we assume the same pattern existed among the children of nonrespondents, 66 children with an ASD may not have been included as early as they should have been in the annual prevalence estimates. This may have contributed to an increase in the observed prevalence over the study period. It is important to note, however, that if the same pattern held in the years following 2008, we may also be missing cases from the prevalence estimates for later years of the study period. In other words, the methods we used to identify cases

may have resulted in an underestimate of ASD prevalence in all years of the study period, not just the earlier years, so we cannot directly ascertain the impact on *changes* in prevalence. However, the issue noted above occurred almost exclusively in the 2–4 and 5–9 year age groups. Accordingly, it is less likely to be an explanation for observed increases in prevalence among the 10- to 14-year-olds.

We found no discrepancies between what parents and agencies reported in terms of whether a child died, moved from the province, or had his or her diagnosis of ASD removed. It seems unlikely, therefore, that mistakenly retaining cases in the numerator contributed to increases in prevalence.

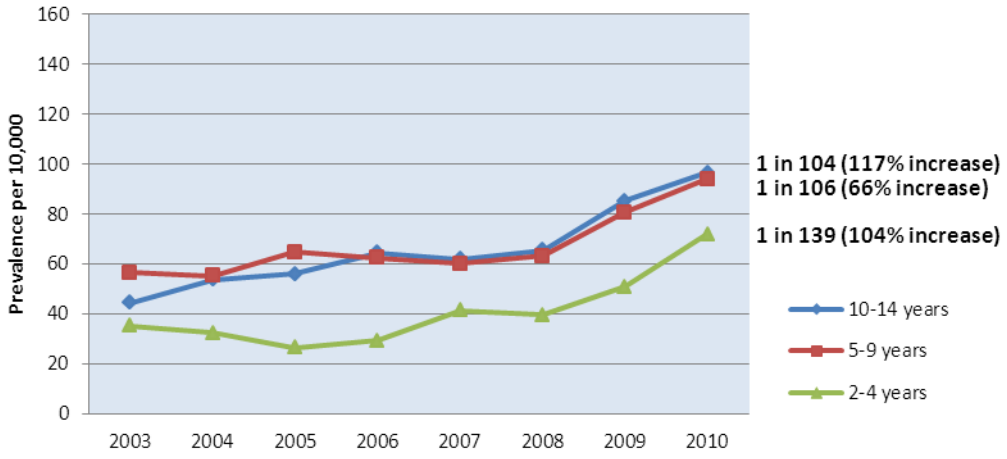
SUMMARY

In Newfoundland and Labrador, the prevalence of ASDs increased significantly between 2003 and 2008 for the two older age groups, and was very close to statistical significance for the 2–4 year age group. The boy:girl ratio was 4.0 in 2003 and 4.6 in 2008, which indicates that the overall prevalence increased relatively more among boys than girls. The following factors did not appear to play a role in terms of explaining the observed increases in prevalence: earlier age at diagnosis; mistakenly retaining cases in the numerator after they should have been removed; or a net in-migration of children with ASDs over the study period. However, greater detection of children with milder forms of ASD in the latter part of the study period may have contributed to increases in prevalence.

Findings for Prince Edward Island

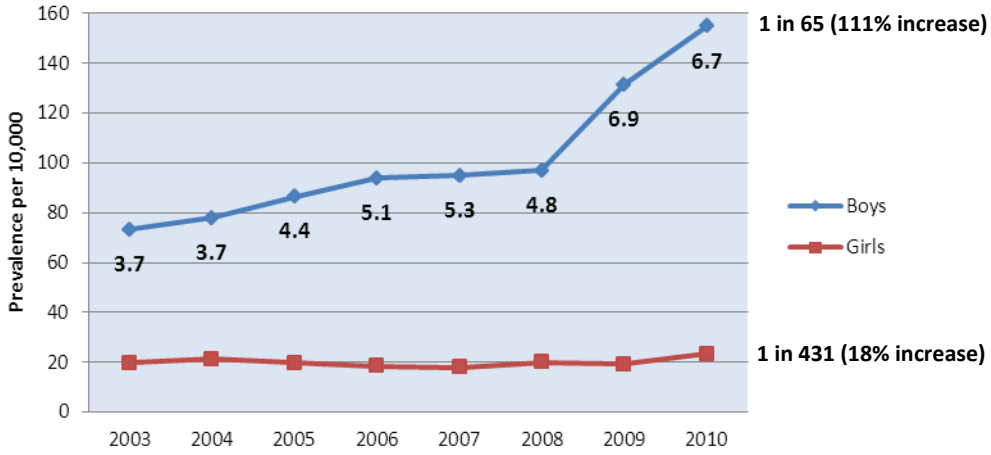
In Prince Edward Island, 269 children with an ASD were identified in at least one year between 2003 and 2010. Consent forms were returned for 122 of these children (45.4%). Prevalence estimates for each year by a) age group and b) sex are shown in the graphs below (Table 4 on p.21 gives the numbers used to calculate these estimates). The y-axis represents the prevalence per 10,000 children. To convert "x per 10,000" to "1 in x" figures (which are shown in bold for the final data point in each series), divide 10,000 by the prevalence. (For example, the prevalence per 10,000 children 5–9 years of age in 2010 was 94.1. If you divide 10,000 by this number (=106), the prevalence can also be reported as 1 in 106 for this age group.) The overall prevalence (for children 2–14 years of age) is not shown in the following graph, but in 2003 it was 47.2 per 10,000 compared to 90.6 per 10,000 in 2010.

Figure 6. Estimated prevalence of autism spectrum disorders in Prince Edward Island by age group (2003–2010)[a]



Note: The numbers on the right show the prevalence expressed in terms of "1 in x children" for 2010. The information in brackets shows the percent change in prevalence between the first and last years of the study period.

Figure 7. Estimated prevalence of autism spectrum disorders in Prince Edward Island by sex, and boy:girl ratio (2003–2010)[a]



Note: The values below each data point indicate the number of boys with an autism spectrum disorder for every girl. The numbers on the right show the prevalence expressed in terms of "1 in x children" for 2010. The

[a] See page 21 for the number of cases of ASD identified and the population estimates used to calculate the prevalence.

information in brackets shows the percent change in prevalence between the first and last years of the study period.

1. How accurate are our prevalence estimates for Prince Edward Island?

a. How likely is it that we are identifying all children 2 to 14 years of age diagnosed with an ASD?

In Prince Edward Island, data for NEDSAC were originally provided by a) the Department of Health and Social Services (and later, the Department of Social Services and Seniors) for children receiving provincially funded intensive behavioural intervention services; and b) the Department of Education. In 2008, some government departments were reorganized and the Department of Education and Early Childhood Development was formed; all cases were subsequently reported by that one agency. It is likely that NEDSAC captures most children diagnosed with an ASD in Prince Edward Island: all preschoolers on the autism spectrum are eligible for provincially funded intensive behavioural intervention services, and the Education data include children who attended private schools or were home schooled.

b. Are all those identified really cases?

Thirteen children from Prince Edward Island were assessed using the Autism Diagnostic Interview or the Autism Diagnostic Observation Schedule. All met the criteria for "Autism".

c. Did the methods we used to identify cases affect the accuracy of our prevalence estimates?

For 19 children of respondents (15.6%), the prevalence year provided by the agency was later than the year parents reported that the child was first living in the province and had an ASD diagnosis. This means that some children of nonrespondents may not have been included as early as they should have been in the annual prevalence estimates.

There were no instances where the Department of Education and Early Childhood Development failed to inform us that a child moved, had his or her diagnosis removed, or died (based on information provided by respondents). If we assume the situation was the same for nonrespondents, then it is unlikely cases were mistakenly included in prevalence estimates for any of the study years.

2. Did the prevalence change over the study period?

When we did statistical tests to compare the prevalence in 2010 with the prevalence in 2003, we found a statistically significant increase for all age groups.

3. What factors might have contributed to the observed increases in prevalence?

a. Diagnostic changes

Table 2 and Figure 8 below, which are based on information provided by respondents for children newly diagnosed during the study period, indicate that children with ASDs tended to be diagnosed at a later age in the second half of the study period compared to the first half (based on a comparison of the median age at diagnosis and the proportion of new diagnoses that were made before a child's fifth birthday). As noted previously, an *earlier* age at diagnosis in the latter part of the study period might result in an increase in prevalence among the 2–4 year age group. Accordingly, the data do

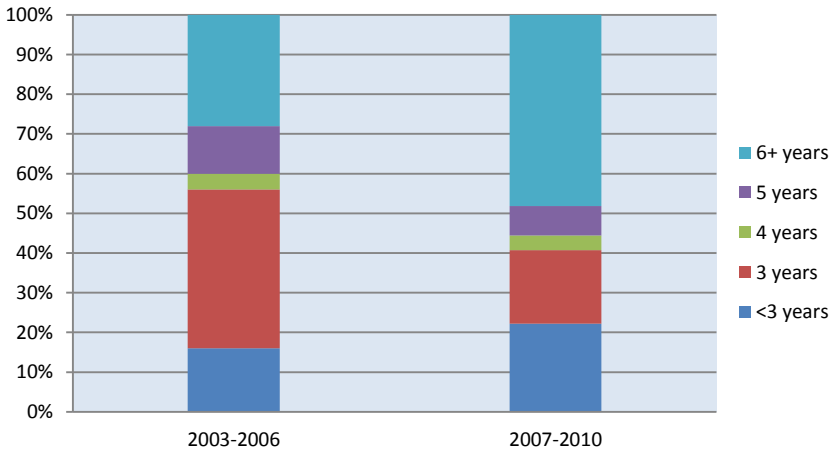
not support age at diagnosis as an explanation for the increase in prevalence in the younger age group. (It is important to note, however, that the table and figure only include information provided by respondents, and do not necessarily reflect the diagnostic situation among the children of nonrespondents.)

Table 2. Age at diagnosis (based on information provided by respondents who were diagnosed in Prince Edward Island between 2003 and 2010 and where an age at initial diagnosis could be calculated; n=52)

	Median, months (range)
2003–2010	55.0 (19–164)
2003–2006	45.0 (19–164)
2007–2010	71.0 (29–154)*
Boys, 2003–2010	55.0 (19–163)
Girls, 2003–2010	---†

**There was no statistically significant difference in the age at diagnosis when comparing children diagnosed in 2003–2006 and 2007–2010. Note that this may be due to the relatively small sample size, which may have made it difficult to detect a statistical effect.*
†Not reported due to small numbers

Figure 8. Proportion of children diagnosed with an autism spectrum disorder at different ages during first and second halves of study period (based on information provided by respondents and where an age at initial diagnosis could be calculated; n=52)



There was no statistically significant difference in the proportion of diagnoses made before age 5 when comparing children diagnosed in 2003–2006 and 2007–2010. Note that this may be due to the relatively small sample size, which may have made it difficult to detect a statistical effect.

b. Changes in the numerator used to calculate prevalence during the study period because cases moved into the region after 2003, or moved from the region, had their diagnosis removed, or died before their 15th birthday

Among the 122 children of respondents, 8 (6.6%) moved to Prince Edward Island after 2003. If we assume the situation was the same for the children of nonrespondents, another 10 individuals may have been added to the numerators used to calculate prevalence in 2004 or later because of migration into the province. In contrast, of the 269 cases identified overall, 14 were removed from the numerator before 2010 because

the family moved from the province, the diagnosis of ASD was removed, or the individual dropped out of school and we could no longer ascertain whether he or she still resided in the province. Thus, over the study period we estimate that 18 individuals were added to the numerator at some point after 2003 and 14 were removed from the numerator at some point before 2010 for reasons that cannot be attributed to changes in incidence. If our assumptions are correct, these factors would have caused a net increase in the numerators used to calculate prevalence.

c. The methods used to identify cases

For 19 children of respondents (15.6%), the prevalence year provided by the agency was later than the year parents reported that the child was first living in the region and had an ASD diagnosis. We could include these children in the numerator for the correct year because of the information provided by parents. However, if we assume the same pattern existed among the children of nonrespondents, 23 children with an ASD may not have been included as early as they should have been in the annual prevalence estimates. This may have contributed to an increase in the observed prevalence over the study period. It is important to note, however, that if the same pattern held in the years following 2010, we may also be missing cases from the prevalence estimates for later years of the study period. In other words, the methods we used to identify cases may have resulted in an underestimate of ASD prevalence in all years of the study period, not just the earlier years, so we cannot directly ascertain the impact on *changes* in prevalence. However, the issue noted above occurred most frequently in the 2–4 and 5–9 year age groups. Accordingly, it is less likely to be an explanation for observed increases in prevalence among the 10- to 14-year-olds.

We found no discrepancies between what parents and the Department of Education and Early Childhood Development reported in terms of whether a child died, moved from the province, or had his or her diagnosis of ASD removed. It seems unlikely, therefore, that mistakenly retaining cases in the numerator contributed to increases in prevalence.

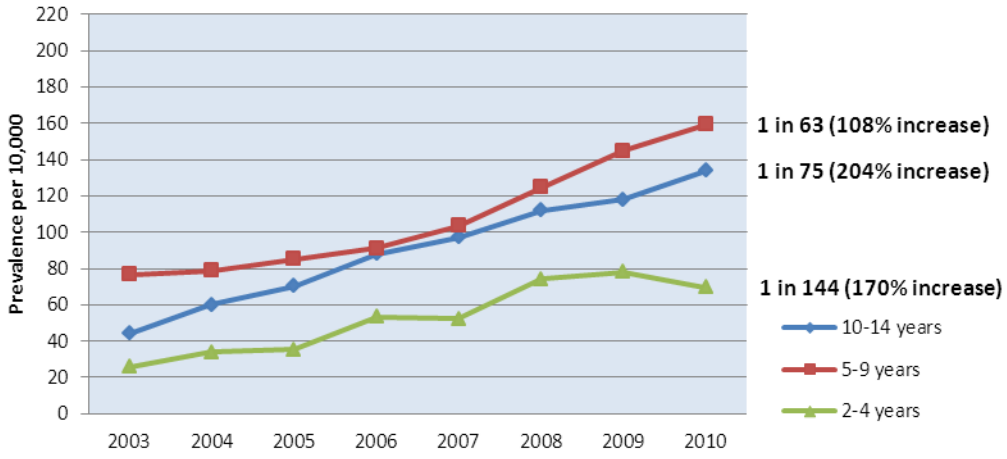
SUMMARY

In Prince Edward Island, the prevalence of ASDs increased significantly between 2003 and 2010 for all the age groups examined. The boy:girl ratio fluctuated from 3.7 to 6.9 (with the higher ratios occurring in the final two years of the study period). This indicates that the overall prevalence increased relatively more among boys than girls. Neither an earlier age at diagnosis in the second half of the study period, nor mistakenly retaining cases in the numerator after they should have been removed, appeared to play a role in terms of explaining the observed increases in prevalence. However, some of the increase may have been due to a net in-migration of children with ASDs to the province during the study period.

Findings for Southeastern Ontario

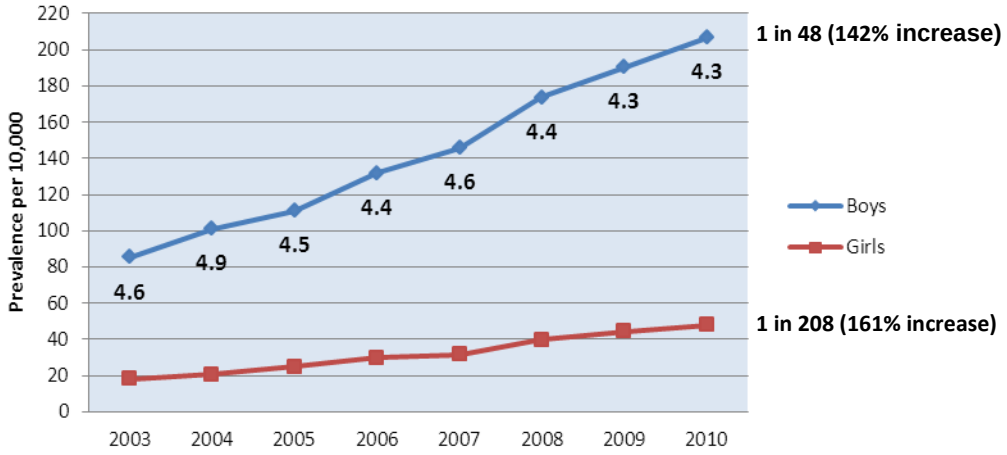
In Southeastern Ontario, 1408 children with an ASD were identified in at least one year between 2003 and 2010. Consent forms were returned for 399 of these children (28.3%). Prevalence estimates for each year by a) age group and b) sex are shown in the graphs below (Table 4 on p.21 gives the numbers used to calculate these estimates). The y-axis represents the prevalence per 10,000 children. To convert "x per 10,000" to "1 in x" figures (which are shown in bold for the final data point in each series), divide 10,000 by the prevalence. (For example, the prevalence per 10,000 children 5–9 years of age in 2010 was 159.4. If you divide 10,000 by 159.4 (=63), the prevalence can also be reported as 1 in 63 for this age group.) The overall prevalence (for children 2–14 years of age) is not shown in the following graph, but in 2003 it was 52.7 per 10,000 compared to 129.2 per 10,000 in 2010.

Figure 9. Estimated prevalence of autism spectrum disorders in Southeastern Ontario by age group (2003–2010)[a]



Note: The numbers on the right show the prevalence expressed in terms of "1 in x children" for 2010. The information in brackets shows the percent change in prevalence between the first and last years of the study period.

Figure 10. Estimated prevalence of autism spectrum disorders in Southeastern Ontario by sex, and boy:girl ratio (2003–2010)[a]



Note: The values below each data point indicate the number of boys with an autism spectrum disorder for every girl. The numbers on the right show the prevalence expressed in terms of "1 in x children" for 2010. The

[a] See page 21 for the number of cases of ASD identified and the population estimates used to calculate the prevalence.

Findings for Southeastern Ontario

information in brackets shows the percent change in prevalence between the first and last years of the study period.

1. **How accurate are our prevalence estimates for Southeastern Ontario?**

    a. **How likely is it that we are identifying all children 2 to 14 years of age diagnosed with an ASD?**

    In Southeastern Ontario, data for NEDSAC were provided by a) Pathways for Children & Youth (the agency that delivers the provincially funded intensive behavioural intervention program for Southeastern Ontario); b) the Child Development Centre at Hotel Dieu Hospital in Kingston, Ontario (the main referral and assessment centre for children in Southeastern Ontario with suspected developmental problems); and c) the five English-language[a] and two French-language[b] school boards serving the region. In Ontario, only children on the moderate to severe end of the autism spectrum are eligible for provincially funded intensive behavioural intervention services. Unless these children were assessed at the Child Development Centre, they may not have been identified to NEDSAC until they started school. Children who were home-schooled or attended private school may not have been captured unless they were diagnosed at the Child Development Centre or eligible for provincially funded intensive behavioural intervention services.

    b. **Are all those identified really cases?**

    Ninety-five children from Southeastern Ontario were assessed using the Autism Diagnostic Interview or the Autism Diagnostic Observation Schedule. Ninety (94.7%) met the criteria for "Autism" or "ASD".

    c. **Did the methods we used to identify cases affect the accuracy of our prevalence estimates?**

    For 72 children of respondents (18.0%), the prevalence year provided by the agency was later than the year parents reported that the child was first living in Southeastern Ontario and had an ASD diagnosis. This means that some children of nonrespondents may not have been included as early as they should have been in the annual prevalence estimates.

    For 11 children (2.8%), the parents reported the family moved from the region or their child's ASD diagnosis was removed, but we were not informed of this by any of the agencies. If we assume the situation was the same for nonrespondents, then about 28 cases may have been mistakenly included in the numerators used to calculate prevalence after the date when they should have been removed.

2. **Did the prevalence change over the study period?**

    When we did statistical tests to compare the prevalence in 2010 with the prevalence in 2003, we found a statistically significant increase for all age groups.

[a] 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

[b] Conseil des écoles publiques de l'Est de l'Ontario; Conseil des écoles Catholiques de langue Française du Centre-Est

Findings for Southeastern Ontario

3. What factors might have contributed to the observed increases in prevalence?

a. Diagnostic changes

Table 3 and Figure 11 below, which are based on information provided by respondents for children newly diagnosed during the study period, indicate that children with ASDs tended to be diagnosed somewhat later in the second half of the study period compared to the first half (based on a comparison of the median age at diagnosis and the proportion of new diagnoses that were made before a child's fifth birthday). As noted previously, an *earlier* age at diagnosis in the latter part of the study period might result in an increase in the observed prevalence among the 2–4 year age group. Accordingly, the data do not support age at diagnosis as an explanation for the increase in prevalence in the younger age group. (It is important to note, however, that the table and figure only include information provided by respondents and do not necessarily reflect the diagnostic situation among the children of nonrespondents.)

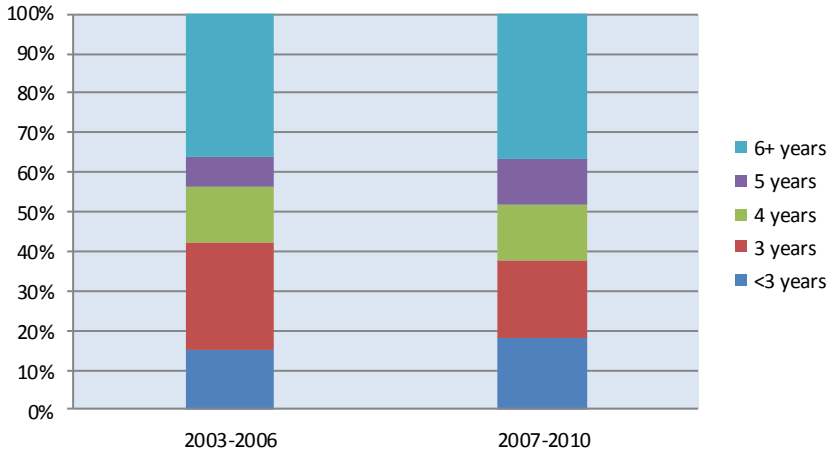
Table 3. Age at diagnosis (based on information provided by respondents who were diagnosed in Southeastern Ontario between 2003 and 2010 and where an age at initial diagnosis could be calculated: n=175)

	Median, months (range)
2003–2010	56.0 (18–172)
2003–2006	53.0 (21–172)
2007–2010	59.0 (18–160)*
Boys, 2003–2010	56.0 (21–172)
Girls, 2003–2010	49.5 (18–156)†

** There was no statistically significant difference in the age at diagnosis when comparing children diagnosed in 2003–2006 and 2007–2010.*

† There was no statistically significant difference in the age at diagnosis for boys and girls.

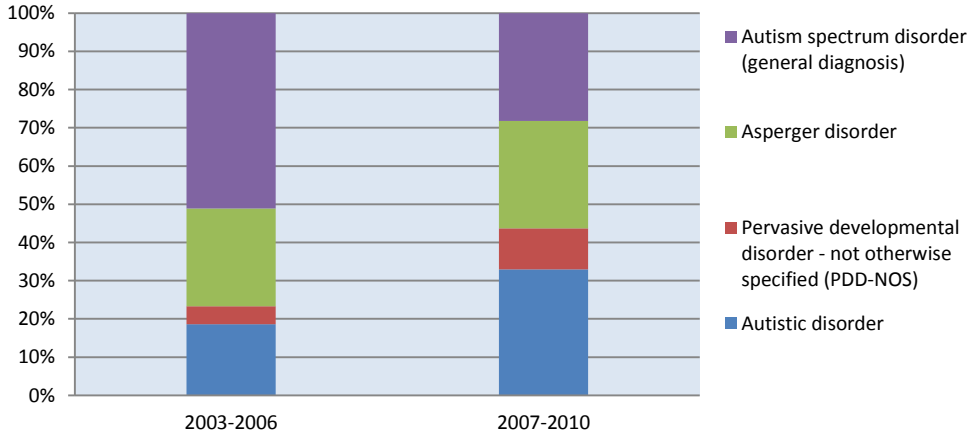
Figure 11. Proportion of children diagnosed with an autism spectrum disorder at different ages during first and second halves of study period (based on information provided by respondents and where an age at initial diagnosis could be calculated: n=175)



There was no statistically significant difference in the proportion of diagnoses made before age 5 when comparing children diagnosed in 2003–2006 and 2007–2010.

Figure 12 below, which is based on information from respondents for children newly diagnosed during the study period, does not support the hypothesis that greater detection of children with milder forms of ASD over the study period contributed to increases in prevalence: the proportion of "autistic disorder" diagnoses (the most severe form of ASD) increased significantly in the second half of the study period.

Figure 12. Diagnostic subtypes for cases diagnosed in Southeastern Ontario during first and second halves of study period (based on information provided by respondents who were diagnosed in Southeastern Ontario between 2003 and 2010; n=189)



There was a statistically significant difference in the proportion of autistic disorder diagnoses when comparing children diagnosed in 2003–2006 and 2007–2010.

b. Changes in the numerator used to calculate prevalence during the study period because cases moved into the region after 2003, or moved from the region, had their diagnosis removed, or died before their 15th birthday

Among the 399 children of respondents, 60 (15.0%) moved to Southeastern Ontario after 2003. If we assume the situation was the same for the children of nonrespondents, another 152 individuals may have been added to the numerators used to calculate prevalence in 2004 or later because of migration into the province. In contrast, of the 1408 cases identified overall, 183 were dropped from the numerator before 2010 because the family moved from the province, the diagnosis of ASD was removed, the child died, or he or she was discharged by the reporting agency and we could no longer confirm residence in the region. Thus, over the study period, we estimate that 212 individuals were added to the numerator at some point after 2003 and 183 were removed from the numerator at some point before 2010 for reasons that cannot be attributed to changes in incidence. If our assumptions are correct, these factors would have caused a net increase in the numerators used to calculate prevalence.

c. The methods used to identify cases

For 72 children of respondents (18.0%), the prevalence year provided by the agency was later than the year parents reported that the child was first living in the region and had an ASD diagnosis. We could include these children in the numerator for the correct year because of the information provided by parents. However, if we assume the same pattern existed among the children of nonrespondents, 182 children with an ASD may

not have been included as early as they should have been in the annual prevalence estimates. This may have contributed to an increase in prevalence over the study period. It is important to note, however, that if the same pattern held in the years following 2010, we may also be missing cases from the prevalence estimates for later years of the study period. In other words, the methods we used to identify cases may have resulted in an underestimate of prevalence in all years of the study period, not just the earlier years, so we cannot directly ascertain the impact on *changes* in prevalence for any of the age groups examined.

As previously noted, in 11 instances (2.8%) the parents reported the family had moved from the region or the ASD diagnosis was removed but we were not informed of this by any of the agencies. If we assume the situation was the same for nonrespondents, approximately 28 cases may have been retained in the numerators used to calculate prevalence after the date when they should have been removed.

SUMMARY

In Southeastern Ontario, the prevalence of ASDs increased significantly between 2003 and 2010 for all the age groups examined. The overall prevalence increased relatively more among girls than boys. An earlier age at diagnosis and greater detection of milder cases in the second half of the study period did not appear to play a role in terms of explaining the observed increases in prevalence. However, two factors may have contributed to the increases observed: a net in-migration of cases to the area over the study period, and mistakenly retaining cases in the numerators after the date they should have been removed.

SUMMARY POINTS

- In all regions, the prevalence of ASDs increased among all the age groups examined.
- The percent change in prevalence was higher for boys than girls in Newfoundland and Labrador and Prince Edward Island (87% versus 63% and 111% versus 18%, respectively). The Autism and Developmental Disabilities Monitoring (ADDM) Network in the United States reported that the average change in prevalence between 2002 and 2006 was 60% for boys compared to 48% for girls.[4] It noted that the most consistent pattern across sites was the increased prevalence among boys, and suggested this may reflect a growing risk among males (although it cautioned that more data are needed to evaluate this). In contrast, the ADDM Network found more variation in prevalence changes among girls between 2002 and 2006. Such variation could be due to improved recognition of ASD symptoms in girls rather than an increase in risk.[4]
- In Southeastern Ontario, the prevalence among the younger age group (2–4 years) appeared to be levelling off in the final years of the study period, and in Newfoundland and Labrador the prevalence decreased between the last two years of the study period for this age group. Prevalence trends should be monitored in younger age groups born at a time when awareness of autism was already high; evidence of a continued increase in prevalence in these groups would provide greater support for a true increase in the occurrence of ASDs.[3,6] A changing age at diagnosis could affect the measured prevalence in younger children, however, so monitoring trends to see if there is any levelling off of prevalence should include children older than 4 years of age. No levelling-off effect was observed in Prince Edward Island for any age group.
- In Newfoundland and Labrador and Prince Edward Island, the prevalence in the final year of the study period for children 5–9 years of age (1 in 93 and 1 in 106, respectively) was higher than the average prevalence reported by the ADDM Network for 8-year-olds in 2006 (1 in 110).[4] However, a recent study reported that 1 in 77 8-year-olds living in Utah was identified with autism in 2008.[7] The prevalence among children 5–9 years of age was much higher in Southeastern Ontario (1 in 63) than in the other regions, but we suspect this may be partly due to agencies failing to inform us when cases moved from the region.
- The boy:girl ratios fluctuated more in Prince Edward Island than in the other two regions, but all ratios were consistent with the range reported by the ADDM Network for its 2006 surveillance year (3.2:1 to 7.6:1).[4]
- In all regions, a substantial proportion of children (44%–56%) diagnosed during the second half of the study period were not identified until 5 years of age or later. While this finding is based on information from respondents—and therefore we do not know if it reflects the situation for all new diagnoses—it merits further investigation, given the generally recognized importance of early detection.[4]
- We were able to examine some aspects of changing diagnostic practices (age at diagnosis, detection of children with milder forms of autism) and explore their potential impact on increases in prevalence. Based on the information provided by respondents, an earlier age at diagnosis in the second half of the study period did not appear to explain the increases in prevalence in the younger age group. Greater detection of children with milder forms of autism may have partly contributed to increases in prevalence in Newfoundland and Labrador.
- The proportion of children who had their diagnosis removed (0.9%-1.9%) was much lower than the parent-reported proportion of American children and youth aged 3–17 years who were diagnosed with autism but no longer had the diagnosis (38%).[5]

Table 4. Numerators and denominators used to calculate prevalence

Newfoundland & Labrador	2003		2004		2005		2006		2007		2008		2009		2010	
	Total with ASD	Total Population	Total with ASD	Total Population	Total with ASD	Total Population	Total with ASD	Total Population	Total with ASD	Total Population	Total with ASD	Total Population	Total with ASD	Total Population	Total with ASD	Total Population
2-4 Years	61	14975	46	14752	52	14329	70	14081	87	13804	78	13780	---	---	---	---
5-9 Years	153	27460	166	26832	198	26434	221	25778	244	25284	271	25061	---	---	---	---
10-14 Years	131	33283	133	32215	136	30550	159	29289	190	28465	205	27942	---	---	---	---
Overall (2-14 Years)	345	75718	345	73799	386	71313	450	69148	521	67553	554	66783	---	---	---	---
Boys	279	38919	281	37912	317	36610	371	35501	425	34693	459	34293	---	---	---	---
Girls	66	36799	64	35887	69	34703	79	33647	96	32860	95	32490	---	---	---	---
Prince Edward Island																
2-4 Years	16	4529	14	4319	11	4142	12	4095	17	4100	16	4053	21	4133	30	4165
5-9 Years	48	8482	46	8337	53	8193	49	7851	46	7634	48	7606	61	7548	70	7440
10-14 Years	44	9872	52	9670	53	9438	60	9314	56	9036	58	8833	75	8786	84	8695
Overall (2-14 Years)	108	22883	112	22326	117	21773	121	21260	119	20770	122	20492	157	20467	184	20300
Boys	86	11742	89	11432	96	11094	102	10866	101	10637	102	10524	138	10504	161	10398
Girls	22	11141	23	10894	21	10679	19	10394	18	10133	20	9968	19	9963	23	9902
Southeastern Ontario																
2-4 Years	41	15885	52	15358	53	14939	79	14847	79	15077	113	15202	120	15331	107	15379
5-9 Years	234	30524	233	29535	241	28318	248	27185	275	26550	325	26076	375	25867	413	25917
10-14 Years	155	35127	210	34963	243	34475	294	33444	311	32011	341	30428	346	29337	378	28190
Overall (2-14 Years)	430	81536	495	79856	537	77732	621	75476	665	73638	779	71706	841	70535	898	69486
Boys	357	41800	414	40948	443	39855	511	38750	552	37852	640	36831	689	36211	735	35550
Girls	73	39736	81	38908	94	37877	110	36726	113	35786	139	34875	152	34324	163	33936

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