Understanding autism data in the Canadian Chronic Disease Surveillance System

This document outlines how the Canadian Chronic Disease Surveillance System (CCDSS) contributes to the collection and reporting of data on autism in Canada. It is intended to help readers understand and use autism data from the CCDSS Data Tool to support efforts across various sectors, such as the health, education, social services, and research sectors. Prepared for the first release of the CCDSS autism data in the fall of 2025, this document includes data up to the 2023–2024 fiscal year.[i] The most recent data are available through the online Data Tool.

The CCDSS was originally designed to track chronic diseases and conditions. As a result, some language in the Data Tool may not reflect the preferences of all Autistic people (see Language considerations for definitions of key terms). Autism is a neurodevelopmental condition not a chronic disease, but it was included in the CCDSS to take advantage of the system's well established infrastructure. Built in partnership with all 13 provinces and territories and guided by rigorous scientific methods, the CCDSS monitors long-term trends of chronic condition-related indicators. This makes it an ideal platform for the public health surveillance of autism and offers a valuable opportunity to address longstanding data gaps identified by the Autistic community.

What is the Canadian Chronic Disease Surveillance System?

The CCDSS is a collaborative network of provincial and territorial surveillance systems supported by the Public Health Agency of Canada.

In each province and territory, the health insurance registry database is linked to the physician claim and hospitalization databases using the health card number. Where applicable, the prescription drug database is also linked. Case definitions are applied to these linked databases to identify people with selected chronic diseases, conditions, and health events.

Anonymized aggregate data are sent to the Public Health Agency of Canada to estimate the incidence, prevalence, all-cause mortality, and/or use of healthcare services for over 20 chronic diseases, conditions, and health events. These data are reported annually and publicly available via the Data Tool.

More information about the CCDSS, including methods and data confidentiality procedures, can be found on the Summary of methods page.

[i] The CCDSS data are reported by fiscal year, April 1 to March 31.

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How is autism data included in the Canadian Chronic Disease Surveillance System?

An autism-specific case definition, based on corresponding International Classification of Diseases (ICD) codes recorded in hospital discharge abstracts and physician claims, was developed by a pan-Canadian group of experts.[ii] This case definition applies only to children and youth aged 1 to 19. No case definition could reliably identify Autistic adults in health administrative data.

Autism case definition

A person aged 1 to 19 years is considered to be Autistic if they meet either of the following criteria:

- At least one hospitalization with an autism ICD code* recorded in any diagnostic field, **OR**
- Two or more physician visits with an autism ICD code* recorded in the first diagnostic field.

*Autism ICD codes:

- International Statistical Classification of Diseases, Ninth Revision (ICD-9): 299.x Pervasive developmental disorders.
- International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Canadian Modification (ICD-10-CA): F84.x Pervasive developmental disorders.

In the first year a child or youth meets the CCDSS case definition for autism, they are considered newly identified (referred to as "incidence" in other conditions). In subsequent years, they are considered an existing case, which allows for estimating the total number of children and youth with autism (prevalence).

Not all children and youth diagnosed with autism are identified within the publicly funded healthcare system. Some receive a diagnosis through private healthcare (e.g., private psychology clinics), the education system, or research institutions (e.g., hospital- or university-based autism research programs). These diagnoses may not be included in the CCDSS data, which could lead to underestimating the number of children and youth with autism.

[ii] Results from a validation study of this case definition, conducted in Ontario, showed a sensitivity of 65.1%, specificity of 99.5%, positive predictive value of 65.7%, and negative predictive value of 99.5%.

What does the Canadian Chronic Disease Surveillance System data tell us about autism among children and youth in Canada?

The Data Tool provides estimates of the prevalence and newly identified cases of children and youth, based on the CCDSS autism case definition, broken down by age, sex, province and territory, and over time. Highlighted below are four key observations based on autism data up to the 2023–2024 fiscal year.[iii,iv]

Autism estimates have increased over time:

Over the past two decades, data show a rise in the number of children and youth meeting the CCDSS case definition for autism in Canada.

- Prevalence estimates of autism in children and youth went from 1 in 714 (0.14%) in 2000–2001 to 1 in 44 (2.25%) in 2023–2024.
- The rate of newly identified autism cases went from 35 per 100,000 children and youth in 2000–2001 to 365 per 100,000 in 2023–2024.

Several factors may have played a role in the overall rise in newly identified cases and prevalence of autism, such as increased awareness,[1] expanded diagnostic criteria,[2] and guidelines promoting early detection.[3] The specific factors and the extent of their contribution to this rise remain unknown. Nevertheless, the trend observed in the data indicates a growing demand for programs and services to support Autistic people across the lifespan and their families.

Autism estimates vary by province and territory:

Based on the CCDSS data, the prevalence estimates and rates of newly identified autism cases differ across provinces and territories.

- In 2023–2024, the prevalence ranged from 1 in 75 (1.33%) in Saskatchewan to 1 in 34 (2.97%) in Prince Edward Island.
- In the same year, the rate of newly identified cases ranged from 254 per 100,000 children and youth in Nova Scotia to 537 per 100,000 in British Columbia.

The identification of autism cases in the health administrative databases used by the CCDSS may vary across the provinces and territories due to differences in data recording practices, health care access, and autism assessment processes.[4] Despite these differences, data from all provinces and territories included in the CCDSS showed increases in autism estimates over time.

[iii] Data on autism from Nunavut, New Brunswick, and Newfoundland and Labrador were either unavailable or excluded for all years. Data from Yukon were excluded before 2010–2011.

[iv] All estimates presented in this document are crude. While age-standardized estimates are used to account for differences in population age structure when comparing results over time or across provinces and territories, the overall patterns in both the age-standardized and crude estimates in this analysis were comparable. Only crude estimates are presented here since they reflect the profile of autism observed in Canada and across the provinces and territories.

The sex gap in autism estimates is narrowing over time:

Although autism continues to be identified more frequently in males than females based on CCDSS data, overall, the sex gap has been narrowing over time.

- In 2000–2001, there were 4.0 times more new cases of autism in males than females.
- By 2023–2024, there were 2.3 times more new cases in males than females.

In alignment with recent research results in other countries,[5,6] this trend suggests an increasing recognition and diagnosis of autism in females over time.

Autism identified at younger ages:

While autism prevalence in the CCDSS remains lower in children aged 1–4 years compared to older age groups, the rate of newly identified autism cases is now highest among the youngest children and has been increasing over time.

- From 2000–2001 to 2011–2012, the rate of newly identified autism cases was similar in children aged 1–4 and 5–9 (e.g., 161 per 100,000 versus 156 per 100,000 in 2011–2012).
- By 2023–2024, the rate of newly identified cases in the 1–4 age group had increased to 689 per 100,000, surpassing the 5–9 age group which reached 489 per 100,000.

This shift highlights a growing emphasis on early identification and diagnosis, which can lead to earlier support for children to help them reach their full abilities.[3]

How is the Public Health Agency of Canada using these data?

The Public Health Agency of Canada currently relies on two data sources for the public health surveillance of autism in children and youth in Canada: the CCDSS and the Canadian Health Survey of Children and Youth (CHSCY). As these sources use different methods of data collection (health administrative data versus self-reported survey data), variations in prevalence estimates are expected. Despite these differences, both consistently show that autism prevalence:

- has increased over time
- varies across provinces and territories
- is higher among males than females
- is lower in children aged 1–4 years compared to older age groups

Recognizing the unique strengths of each data source, the Public Health Agency of Canada primarily relies on data from the CHSCY to estimate the prevalence of diagnosed autism in children and youth, and to better understand their broader sociodemographic and health profiles. Meanwhile, data from the CCDSS are used to track long-term trends in autism prevalence and the number of newly identified children and youth.

By combining insights from these two national sources, we gain a more complete picture of how many Autistic children and youth live in Canada. This reliable data, both on autism prevalence and newly identified cases, can help identify potential gaps in diagnostic services and inform the development of equitable public health strategies.

Professionals such as healthcare providers, educators, and social workers use insights from this data to guide decisions that address the needs of Autistic children, youth, and their families. This data also provides a strong foundation for future research and innovation aimed at enhancing support for the autism community.

Language considerations

The Government of Canada recognizes that preferences differ on the use of person-first ('children and youth with autism') versus identity-first ('Autistic children and youth') language. To acknowledge these diverse views, this document uses both identity-first and person-first language. That said, some terminology used in the Data Tool may not fully reflect the language preferences of all Autistic people, since the CCDSS was originally designed to track chronic diseases and conditions.

The following provides explanations of key terms used in the Data Tool, as relevant in the context of autism:

- **Chronic disease:** A chronic disease, sometimes called a noncommunicable disease, is a long-lasting health condition that can be caused by things like genetics, biological or physical factors, lifestyle, or the environment. The CCDSS tracks more than 20 health conditions using health system data. While autism is a neurodevelopmental condition, not a chronic disease, it is included in the CCDSS to take advantage of the system's proven infrastructure.
- **Surveillance:** Public health surveillance, a core function of the Public Health Agency of Canada, involves the ongoing, systematic collection, analysis, interpretation, and dissemination of health-related data essential to planning, implementation, and evaluation of public health practice. The CCDSS operationalizes this concept by collecting, analyzing, and disseminating anonymized, aggregate health data from physicians and hospitals to estimate the number of people in Canada with various chronic conditions. In the context of autism, the CCDSS uses a validated case definition to estimate the number of Autistic children and youth in Canada.
- **Incidence:** Incidence is the number of new cases of a disease or condition during a certain period of time in the population at risk. In the CCDSS, incidence refers to the number of people who have met the case definition for the first time, within a fiscal year and among a population at risk, expressed as a rate. For autism, the only neurodevelopmental condition in the CCDSS, the term "newly identified case" is used instead of "incidence" to acknowledge that the characteristics of autism typically become apparent during early childhood, without a distinct point of onset.

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