Autism Spectrum Disorder Surveillance in Québec

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Bureau d'information et d'études en santé des populations

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AUTHORS

Fatoumata Binta Diallo
Louis Rochette
Éric Pelletier
Unité surveillance des troubles mentaux et des maladies neurologiques
Bureau d'information et d'études en santé des populations
Institut national de santé publique du Québec

Alain Lesage
Unité surveillance des troubles mentaux et des maladies neurologiques
Bureau d'information et d'études en santé des populations
Institut national de santé publique du Québec
and
Institut universitaire en santé mentale de Montréal

WITH THE COLLABORATION OF

Manon Noiseux
Direction de santé publique – Surveillance de l'état de santé de la population
Centre de santé et de services sociaux de la Montérégie-Centre

Mélina Rivard
Département de psychologie – Laboratoire ÉPAULARD
Université du Québec à Montréal

Alexis Beauchamp-Châtel
Centre intégré de santé et de services sociaux de l'Est-de-l'Île-de-Montréal
Université de Montréal

PAGE LAYOUT

Sylvie Muller
Bureau d'information et d'études en santé des populations

TRANSLATOR

Stevenson&Writers

LINGUISTIC REVISION

Émilie Pelletier

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ICD	International Classification of Diseases
DSM	Diagnostic and Statistical Manual of Mental Disorders
INSPQ	Institut national de santé publique du Québec
MED-ÉCHO	Maintenance et exploitation des données pour l'étude de la clientèle hospitalière
MEES	Ministère de l'Éducation et de l'Enseignement supérieur (previously named the Ministère de l'Éducation, du Loisir et du Sport)
MSSS	Ministère de la Santé et des Services sociaux
RAMQ	Régie de l'assurance maladie du Québec
QICDSS	Québec Integrated Chronic Disease Surveillance System
ADHD	Attention Deficit or Hyperactivity Disorder
PDD	Pervasive Developmental Disorders
ASD	Autism Spectrum Disorder

Highlights

This report discusses the prevalence and the incidence rate of autism spectrum disorder (ASD). It also demonstrates the capability of the Québec Integrated Chronic Disease Surveillance System (QICDSS) to identify the comorbidities associated with ASD and the profile of health services utilization. These estimates were obtained from a longitudinal study covering the period from April 1, 2000, to March 31, 2015, for all persons eligible for health coverage between the ages of 1 and 24 years. To be considered to have ASD, the individual must have had at least one medical visit or hospitalization with a principal diagnosis of ASD.

- The results show a constant growth in ASD over time. In 2014-2015, there were nearly 17 000 persons in Québec between the ages of 1 and 17 who have been diagnosed with ASD.

- The prevalence of ASD varies considerably from one region to another, varying from 0.7% to 1.8% among persons aged 4 to 17 years.

- The lifetime prevalence measured by the QICDSS (1.4%) is relatively close to that of the Ministère de l'Éducation et de l'Enseignement supérieur (1.3%), making it possible to use linked medical and administrative sources to track ASD.

- The material disadvantage index does not show a clear relationship with the prevalence of ASD while the social disadvantage index suggests a linear increase in the rate of prevalence of ASD going from the very advantaged to the very disadvantaged.

- The study of concomitant physical and mental illnesses during the first year of life and throughout life indicates, in general, a greater prevalence in persons with ASD when compared to the general population without ASD.

- Pediatricians and psychiatrists are the medical professionals most often consulted by persons with ASD. The types of professionals consulted change depending on the age of the person with ASD. The study of the hierarchical profile of the services used reveals that, with the passage into adulthood, specialized services for mental health decrease and are provided by family doctors.

- With 75 deaths observed over a period of 15 years, the mortality rate among persons with ASD is three times higher than in the general population without ASD.

The information contained in this report provides an unprecedented view of ASD in Québec based on the new monitoring indicators developed under the framework of the QICDSS and offers many new paths for future research. These include, notably, the exploration of the etiology of ASD, the higher mortality observed with this disorder, and the study of the variation in health services availability and the prevalence of ASD.

1 Introduction

Infantile autism was described for the first time by Léo Kanner in 1943 as an affective disorder of communication and relationship that does not impact intelligence (Kanner, 1943). In 1944, Hans Asperger described the disorder as "autistic psychopathy" characterized by quirks and intellectual abilities ranging from debility to genius (Asperger, 1944). Much later, this little-known definition was revived by Lorna Wing who summarized the previous work and proposed the definition of Asperger's syndrome (Wing, 1981). In 1994, the Diagnostic and Statistical Manual of Mental Disorders (DSM-4) proposed the term "pervasive developmental disorders" (PDD) (American Psychiatric Association, 1994), which was revised in 2013 in the 5th edition of the manual (DSM-5). With the goal of addressing the dimensional aspect of this disorder, DSM-5 introduced the notion of autism spectrum disorder (ASD). ASD is defined as a neurodevelopmental condition which is expressed as a deficit in social interactions, unusual development of social communications and a characteristic of limited and repetitive behaviours, interests, and activities (American Psychiatric Association, 2013). It combines a group of conditions including autism disorder, Asperger's syndrome, and non-specific pervasive developmental disorders.

Investigations of the prevalence of ASD show that it has been increasing constantly since the middle of the 1960s. The risk of having ASD is presently estimated at 1% (Anagnostou et al., 2014). The United States Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network estimates ASD prevalence of ASD at 14.6 per 1,000 children aged 8 years in 2012 (Centers for Disease Control and Prevention, 2016). This prevalence varied widely among the regions, ranging from 12.2 per 1,000 children in South Carolina to 24.4 per 1 000 children in New Jersey (where both education and health care records were analyzed): there was therefore a 2-fold variation in prevalence rates. In Québec, the monitoring performed on the database from the ministry of education (MEES; Ministère de l'Éducation et de l'Enseignement supérieur) has shown a prevalence of ASD of 11.2 per 1 000 children in 2012-2013 (Noiseux, 2016). The increase in the prevalence of ASD is attributed largely to changes in the definition, to more accurate diagnosis, to a better awareness among communities and professionals, and to better approaches to detection and services (Anagnostou et al., 2014; Bello, 2007; Chaste & Leboyer, 2012; Duchan & Patel, 2012; Herbert, 2010; Levy, Mandell, & Schultz, 2009).

ASD is being observed early, in the first years of a child's life, and parents often detect symptoms before the age of three. Boys are more likely to be affected than girls (a ratio of 4 to 5 boys for 1 girl according to studies). Many factors are cited as causes in the scientific literature to explain the origin of this disorder: genetic factors (Kochman, Bach, Dereux, Arens, & Garcin, 2010; Levy et al., 2009), obstetric and neonatal conditions (Gardener, Spiegelman, & Buka, 2009, 2011; Kolevzon, Gross, & Reichenberg, 2007; Sandin et al., 2012), socioeconomic status (SES) (Lehti et al., 2015; Rai et al., 2012), and place of residence (Leonard et al., 2011). Some hypotheses related to environmental factors, such as vaccination, have been refuted (Fombonne, Zakarian, Bennett, Meng, & McLean-Heywood, 2006), but physical and social environmental factors cannot be discounted and are the subject of continuing research.

ASD is often accompanied by numerous medical and psychiatric conditions (Simonoff et al., 2008). Children with ASD have a higher number of medical visits, are medicated for longer periods of time, have a greater need for treatment and follow-up for emotional, developmental, and behavioural problems, and they are much more likely to require physical therapy or language therapy than are children without autism (Gurney, McPheeters, & Davis, 2006). The number of deaths observed is two to three times higher in populations with ASD than in the general population of the same age and gender (Treating Autism, 2013; Woolfenden, Sarkozy, Ridley, Coory, & Williams, 2012). Even if

improvements occur during development, ASD is a lifelong condition. When children are diagnosed later in life, the access to specialized services is also delayed with, as a consequence, a potential for decreased capabilities, impairment in quality of life, and profound dissatisfaction among families in the policies and services available (Fombonne, 2003).

The objective of this document is to estimate, in Québec, the prevalence and the incidence rate of ASD, the socioeconomic determinants, the concomitant diseases, the utilization of services, and the mortality among children and adolescents based on the linked medical and administrative data. A secondary objective is to compare the results on prevalence obtained with those published in a report by the Direction de la santé publique de la Montérégie using data from the MEES to establish whether the linked medical and administrative databases can be used as a source of information for monitoring ASD in Québec.

2   Methodology

2.1   Data sources

Estimates were produced using data from linked administrative databases of the Régie de l'assurance maladie du Québec (RAMQ) and the Ministère de la Santé et des Services sociaux du Québec (MSSS), which together form the Québec Integrated Chronic Disease Surveillance System (QICDSS) (Blais et al., 2014). The QICDSS contains information sourced from: a) claims from doctors that compile all medical procedures billed to RAMQ; b) registration files for all persons covered by health insurance (FIPA), which contain demographic data as well as the period of their eligibility for health insurance; c) hospitalization records MED-ÉCHO (Maintenance et exploitation des données pour l'étude de la clientèle hospitalière) that record the principal and secondary diagnoses associated with a hospital admission; and d) files on death of the Registre des événements démographiques.

The International Classification of Diseases, Ninth Revision (ICD-9) was used to code diagnoses in the physician billing database for the entire observation period. In the hospitalization database, the ICD-9 was used for the period up to March 31, 2006, and the tenth revision (ICD-10) was used thereafter.

2.2   Identification of cases

The population under study for any given year is composed of all children under 17 years of age who have received a principal diagnosis of ASD between the years 2000 and 2015 and who are eligible for coverage under the health insurance regime of Québec. The population aged 18 to 24 was also analyzed since this condition persists for their entire lifetime. Individuals who have received a principal diagnosis of ASD during the period of observation are considered to be prevalent cases with the disorder. Individuals who have received a first principal diagnosis of ASD are considered to be incident cases for the year under study.

To be considered to have ASD, the individual must have had at least one medical visit or a hospitalization with a principal diagnosis of ASD (codes 299.0, 299.1, 299.8, and 299.9 of the ICD-9 or their equivalent in ICD-10-CA). General practitioners, pediatricians, psychiatrists, or other medical specialists may make the diagnoses found in the files of RAMQ and MED-ÉCHO. Table 1 describes the different ASD diagnoses associated with the different codes found in ICD-9 and ICD-10-CA.

Subjects are considered to be afflicted with a concomitant disease when they have had at least one medical visit or hospitalization with one of the diagnosis codes mentioned in Table 3. A systematic scan and review of the literature guided the choice of concomitant diseases to be studied.

Table 1   **Diagnosis codes for ASD**

Categories of mental disorders	ICD-9	Description ICD-9	ICD-10-CA	Description ICD-10-CA
Autism spectrum disorder (ASD)	299.0	Autistic disorder	F84.0	Childhood autism
	299.1	Disintegrative psychosis	F84.3	Other childhood disintegrative disorder
	299.8	Other specified pervasive developmental disorders	F84.1	Atypical autism
			F84.2	Rett's syndrome
			F84.4	Overactive disorder associated with mental retardation and stereotyped movements
			F84.5	Asperger's syndrome
			F84.8	Other pervasive developmental disorders (PDD)
	299.9	Unspecified pervasive developmental disorder	F84.9	Pervasive developmental disorder, unspecified

The indicator used to evaluate the degree of ASD in the population was the lifetime prevalence. The individual only had to meet the inclusion criteria once during the period of observation in order to be considered a prevalent case of ASD. This choice of lifetime prevalence allows us to demonstrate the chronic and widespread nature of this mental disorder. This is calculated in a cumulative fashion over the course of years and thus includes both recent cases and much older ones. The annual prevalence, which gives a better representation of the workload on health services (which includes only individuals who met the inclusion criteria during the year) was also calculated and will be presented.

2.3   Periods studied and comparisons

The estimates were obtained from a longitudinal study. The period covered by the data begins January 1, 1996. The period of this analysis begins April 1, 2000, and ends March 31, 2015.

The comparisons over time and between regions are made with measured data adjusted for age. The measured data is obtained by direct standardization based on the age structure of the population of Québec in 2001. The ranges of ages considered are: 1-4 years, 5-9 years, 10-14 years, and 15-17 years. The identification of concomitant diseases among persons with ASD and in the general population was done in the first year of life (even though ASD may have been identified later in life) and during their lifetime.

2.4   Definition of socio-economic level

The estimation of socio-economic level is based on geographic indices of social and material disadvantage (Pampalon, Gamache, & Hamel, 2010). The quintile 1 represents the most advantaged regions and, inversely, the quintile 5 represents the most disadvantaged. The measure of disadvantage was realized using the most recent census data at the time of the period studied. Children born from 2000-2001 and 2003-2004 were attributed indices from the census of 2001; children born from 2004-2005 and 2008-2009 from the census of 2006; and children born from 2009-2010 and 2014-2015 from the census of 2011. The analyses were performed jointly and separately

for the material component and for the social component. The material component is defined by the level of schooling attained, employment, and revenue, while the social component is associated with variations in family structure and marital state. Roughly 94% of Québec's population in the QICDSS were given an index of disadvantage in 2014-2015 (most recent files available).

2.5   Definition of medical services

The service utilization profiles are constructed based on the location where the services are provided and according to the specialization of the doctor involved: family doctor (general practitioner), pediatrician, psychiatrist, or other specialist. Information regarding service sites was collected in the physicians' claims database, which classifies institutions. Consequently, private physicians' offices have been distinguished from public institutions and, within hospitals, outpatient, emergency, and psychiatric consultations have been differentiated. Information on the vocation of a hospital in which an individual stayed derives from the hospitalization database.

2.6   Calculation of mortality

The calculation of the number of deaths is based on the mortality data from 1996 to 2011 among persons between 1 and 24 years of age. The analysis of causes of death takes into account deaths occurring during a given year of persons meeting the case definition during the same year. Overall excess mortality by main cause of death for persons with ASD were calculated using age-adjusted mortality rate ratios and are presented according to the status of the person, either suffering or not suffering from an ASD.

2.7   Report published by the Direction de santé publique of the Agence de la santé et des services sociaux de la Montérégie

Since 2007, a regional public health agency has been monitoring ASD using data on handicapped students or those with special needs supplied by the MEES (Noiseux, 2016). The Montérégie is compared to 17 other administrative regions and to Québec as a whole. The student handicapped by ASD is one who has received a diagnosis from a physician or psychologist who has developed expertise in the field and is part of a multidisciplinary team whose overall evaluation has concluded with one of the following diagnoses: autistic disorder, Rett's syndrome, childhood disintegrative disorder, Asperger's syndrome, and unspecified ASD. School commissions account for students with ASD who have a code 50. In order to be coded as such, the student must not only be identified as having ASD, but must also have serious limitations and support measures put in place to mitigate them. The data analyzed covers the school years 2000-2001 to 2014-2015. The rate of prevalence of ASD is calculated as follows: the total number of students with ASD for a given school year divided by the total number of students for the school year multiplied by 10 000.

3 Results

3.1 Prevalence of ASD

The annual prevalence of ASD in children aged 1 to 17 has been growing strongly from 1 per 1 000 in 2000-2001 to more than 4 per 1 000 in 2014-2015 (Figure 1). This prevalence differs according to the sex and the age of the child. It was 7.3 and 1.8 per 1 000 among boys and girls, respectively, in 2014-2015.

In 2014-2015, there were 16 490 children from 1 to 17 years old who had been diagnosed with ASD since 2000. The lifetime prevalence is 12 per 1 000 (Figure 2); or 19 per 1 000 among boys and 5 per 1 000 among girls, equivalent to a ratio of nearly 4 boys to each girl.

Table 2 presents the number of people from 1 to 17 with ASD, as well as the adjusted annual prevalence and the lifetime prevalence according to the Réseau territorial de services (RTS) for the year 2014-2015. The 99% confidence intervals make it easier to evaluate the territorial variations. There is a large difference between the different RTSs ranging from 0 to 7.2 per 1 000 for the annual prevalence and from 6.7 to 17.3 per 1 000 for the lifetime prevalence.

Figure 3 shows the regional lifetime prevalence of ASD among children from 4 to 17 years old taken from data provided by the MEES and presented in the report from the Direction de la santé publique de la Montérégie and the lifetime prevalence data from QICDSS. The lifetime prevalence measured by the QICDSS is relatively close to that of the MEES for many regions. The prevalence for Québec as a whole remains identical in the two sources (13.6 in the QICDSS versus 13.2 in the MEES).

Figure 1   **Annual adjusted diagnosed ASD prevalence for 1- to 17-year-olds, by gender, Québec, 2000-2001 to 2014-2015**
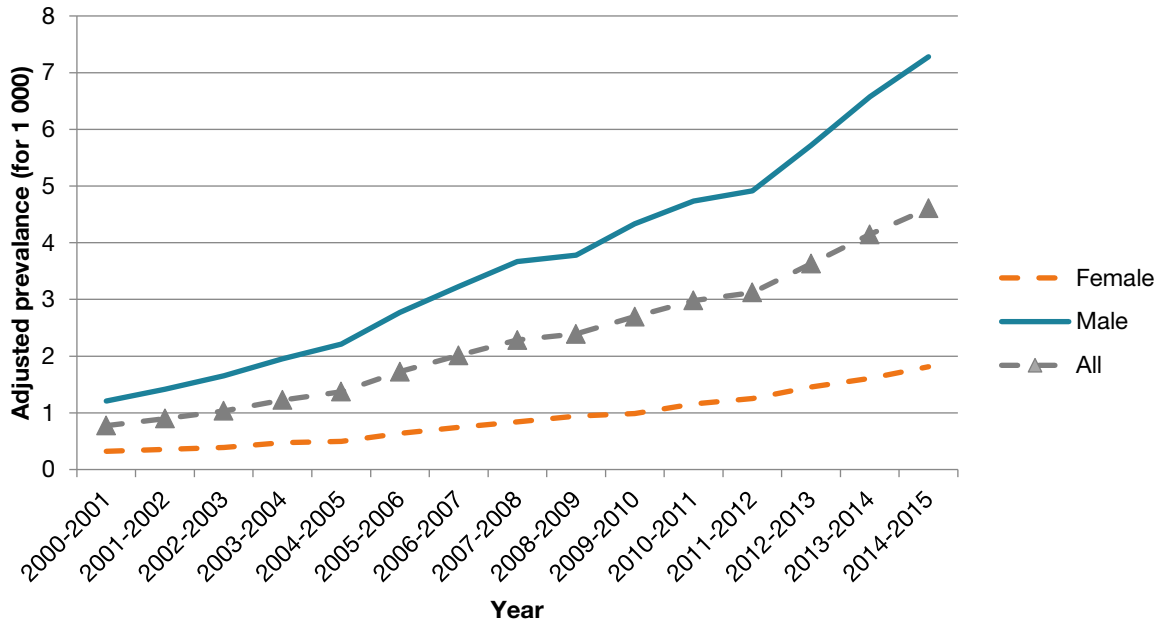
Figure 2   **Lifetime adjusted diagnosed ASD prevalence for 1- to 17-year-olds, by gender, Québec, 2000-2001 to 2014-2015**
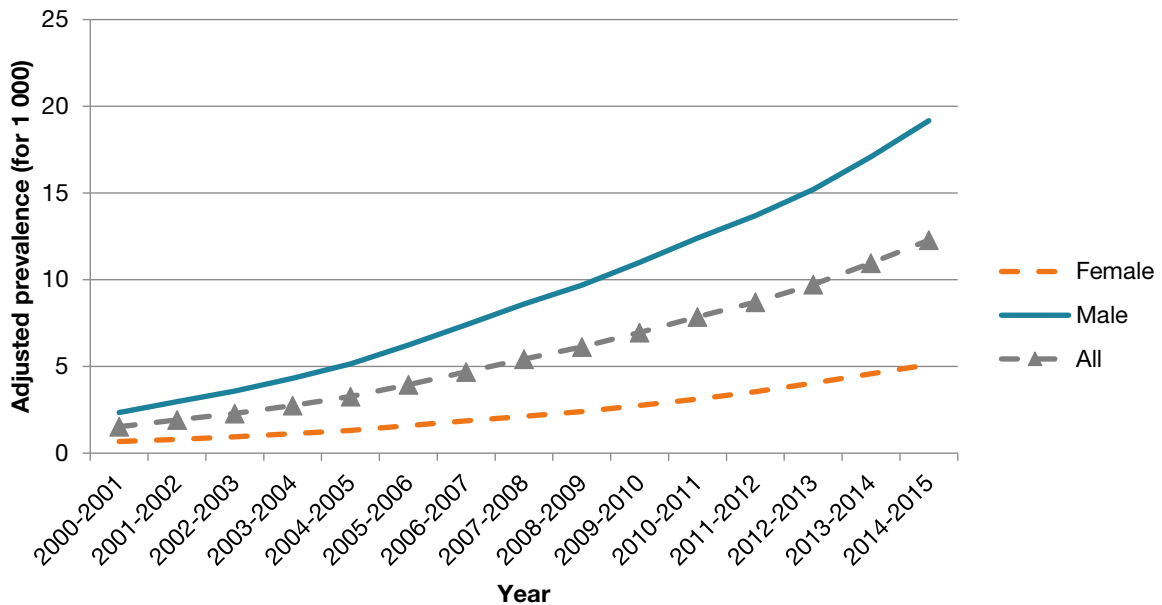
Table 2 **Adjusted number and prevalence, annual and lifetime, of diagnosed ASD among 1- to 17-year-olds, by Réseau territorial de services (RTS), Québec, 2014-2015**

Réseau territorial de services (RTS)	Annual prevalence			Lifetime prevalence		
	Number	Prevalence (per 1 000)	C.I. at 99%	Number	Prevalence (per 1 000)	C.I. at 99%
CISSS du Bas-Saint-Laurent	175	5.7	4.6-7.0	335	11.2	9.7-13.0.
CIUSSS du Saguenay—Lac-Saint-Jean	175	3.9	3.1-4.7	390	8.9	7.8-10.2.
CIUSSS de la Capitale-Nationale	350	3.3	2.8-3.8	750	7.3	6.6-8.0
CIUSSS de la Mauricie-et-du-Centre-du-Québec	255	3.2	2.7-3.8	615	8.2	7.3-9.1
CIUSSS de l'Estrie – Centre hospitalier universitaire	275	3.4	2.9-4.0	1 050	13.5	12.4-14.6
CIUSSS de l'Ouest-de-l'Île-de-Montréal	380	5.4	4.7-6.2	1 050	15.7	14.5-17.1
CIUSSS du Centre-Ouest-de-l'Île-de-Montréal	340	5.6	4.8-6.4	845	14.6	13.3-16.0
CIUSSS du Centre-Sud-de-l'Île-de-Montréal	200	5.5	4.5-6.7	540	16.4	14.5-18.5
CIUSSS du Nord-de-l'Île-de-Montréal	430	5.4	4.7-6.1	1 025	13.8	12.7-15.1
CIUSSS de l'Est-de-l'Île-de-Montréal	495	5.6	4.9-6.4	1 180	14.2	13.1-15.4
CISSS de l'Outaouais	295	3.9	3.3-4.6	700	9.9	8.9-10.9
CISSS de l'Abitibi-Témiscamingue	80	2.8	2.1-3.8	160	6.1	4.9-7.5
CISSS de la Côte-Nord	50	3.2	2.1-4.6	125	7.9	6.2-10.0
CISSS de la Gaspésie	70	6.4	4.6-8.8	120	11.2	8.7-14.3
CISSS des Îles	0	0.0	0.0-0.0	10	6.7	2.6-14.6
CISSS de Chaudière-Appalaches	225	2.9	2.4-3.5	545	7.6	6.8-8.5
CISSS de Laval	480	5.7	5.0-6.4	1 100	13.6	12.6-14.8
CISSS de Lanaudière	300	3.3	2.8-3.8	830	9.5	8.6-10.4
CISSS des Laurentides	620	5.7	5.1-6.4	1 470	14.4	13.4-15.4
CISSS de la Montérégie-Centre	400	5.6	4.8-6.3	1 065	15.7	14.5-17.0
CISSS de la Montérégie-Est	680	7.2	6.5-7.9	1 550	17.3	16.2-18.6
CISSS de la Montérégie-Ouest	420	4.6	4.0-5.2	1 340	15.6	14.5-16.8
QUÉBEC	6 720	4.6	4.5-4.7	16 940	12.3	12.0-12.5

Figure 3   **Lifetime prevalence (per 1 000) of diagnosed ASD for 4- to 17-year-olds, by region, Québec, 2014-2015 (data from QICDSS and MEES)**
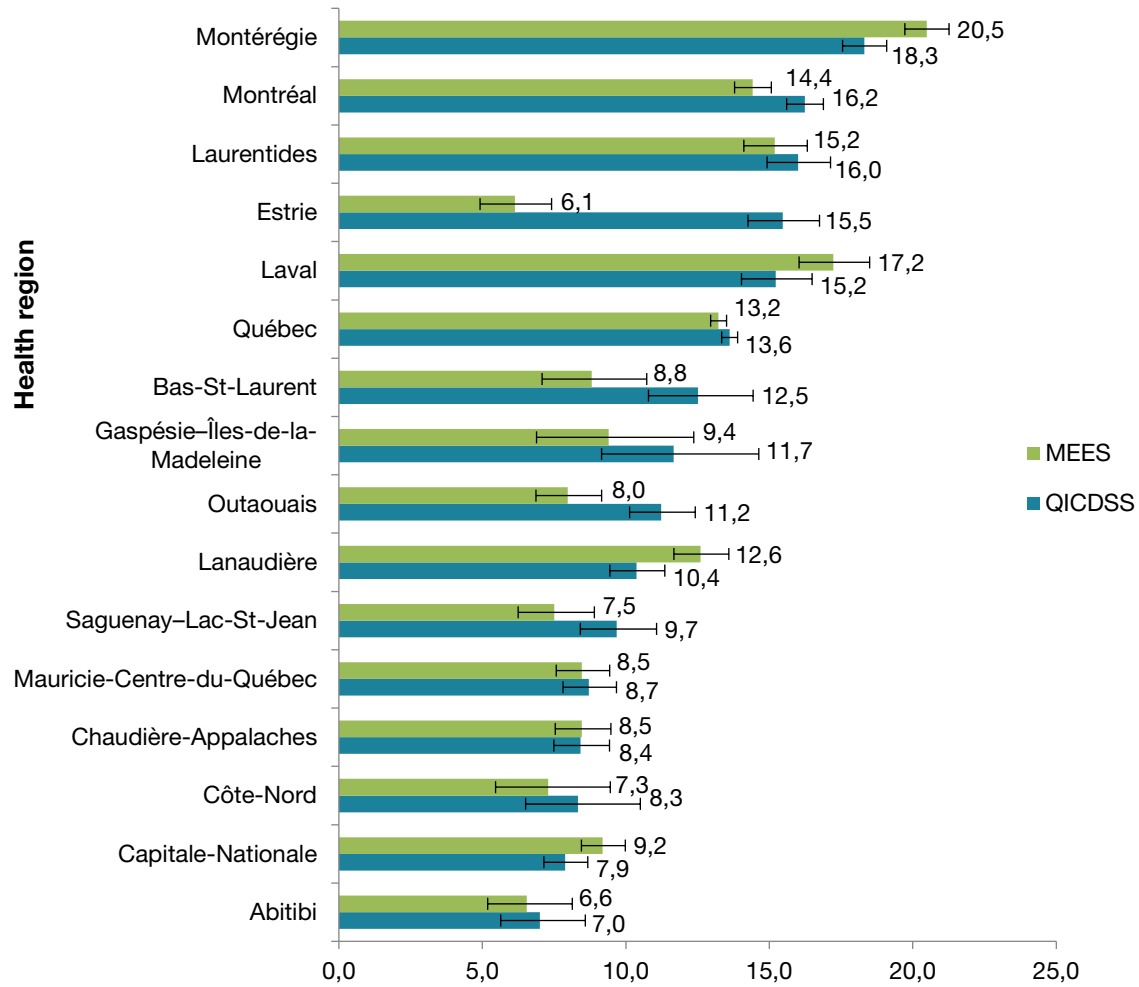
99% confidence interval.

3.2 Incidence rate of ASD

In 2014-2015 there were 2 758 new cases of ASD among persons 17 years old and under (these results were not presented). The incidence rate is 1.9 per 1 000 children. Boys are most often diagnosed and this at a rate almost four times that of girls.

For 2000-2001, as for 2014-2015, the first diagnosis is often made before the age of 5 and the majority are diagnosed before the age of 10 (Figure 4).

Figure 4   Incidence rate of diagnosed ASD among 1- to 24-year-olds according to gender and age, Québec, 2000-2001 and 2014-2015
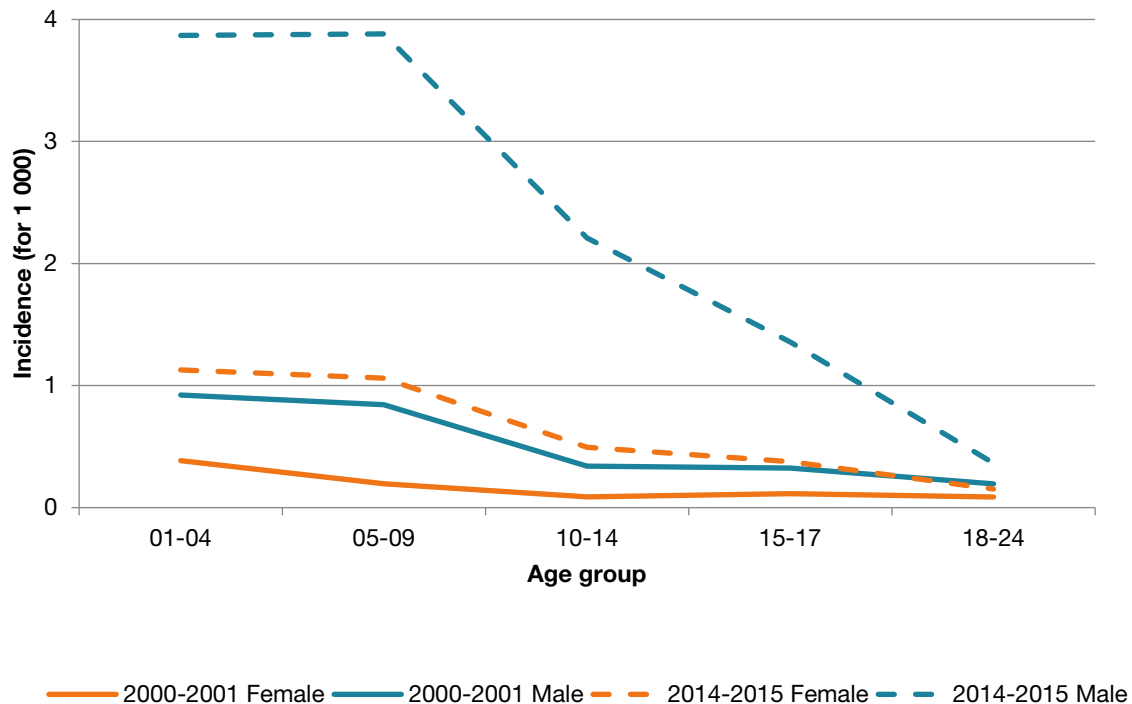
3.3 Prevalence of ASD according to material and social disadvantage index related to the living environment at birth

Figure 5 shows the prevalence of ASD according to the material and social disadvantage index at birth. A complex relationship between the types of disadvantage is observed. A peak is observed in both those who are very disadvantaged on both indices and those who are very advantaged on the material index. Taken separately, the material disadvantage index does not show a clear relationship with the prevalence of ASD while the social disadvantage index suggests a linear increase in the rate of prevalence of ASD going from the very advantaged to the very disadvantaged.

Figure 5 **Lifetime prevalence of diagnosed ASD among 1- to 17-year-olds, according to material and social disadvantage, related to the living environment at birth, Québec, 2014-2015**
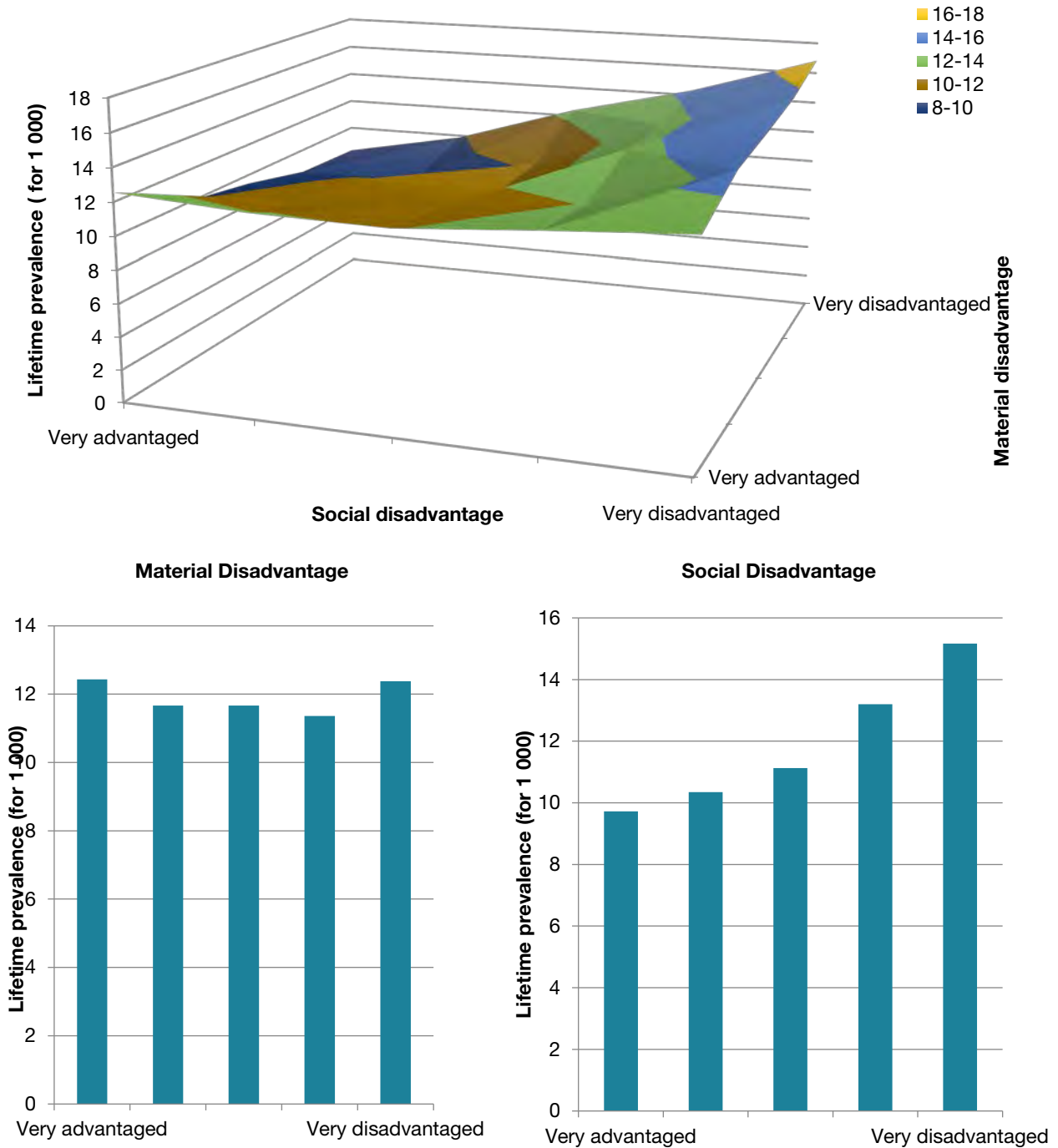
3.4   Concomitant diseases identified among children with ASD

Table 3 shows the concomitant diseases diagnosed in people with ASD (in their first year of life and during their lifetime) and in the general population without ASD for the 2014-2015 period in Québec. The concomitant diseases are presented in the order of their appearance in the codes of the ICD-9. In most cases, the proportion of subjects with a concomitant disease is greater among people with ASD than in the general population and this is true for almost all of the diseases studied.

Table 3   **Prevalence of concomitant disease for persons with or without diagnosed ASD in the first year of life or in their lifetime, 1- to 17-year-olds, Québec, 2014-2015**

	First year of life				During lifetime			
Concomitant diseases (ICD-9 codes)	**With ASD** (n=16 940)		**Without ASD** (n=1 447 660)		**With ASD** (n=16 940)		**Without ASD** (n=1 447 660)	
	%	99% C.I.	(%)	99% C.I.	(%)	99% C.I.	(%)	99% C.I.
Infectious diseases (000-139)	26.9	25.8-27.9	21.4	21.3-21.5	68.0	66.4-69.7	54.2	54.0-54.4
Tumours (140-239)	3.3	2.9-3.7	3.1	3.0-3.1	11.3	10.7-12.0	8.7	8.6-8.7
Endocrinological, nutritional or metabolic diseases, and immune system problems (240-279)	7.1	6.6-7.7	3.7	3.7-3.7	24.9	23.9-25.9	12.4	12.3-12.4
Diabetes (250)	0.2	0.1-0.3	0.1	0.1-0.1	1.2	0.9-1.4	0.5	0.5-0.5
Mental disorders (290-319)	8.8	8.2-9.4	3.5	3.5-3.5	85.2	83.4-87.0	25.3	25.2-25.4
Organic psychotic conditions (290-294)	0.1	0.1-0.2	0.0	0.0-0.0	1.7	1.4-1.9	0.3	0.3-0.3
Problems related to substance abuse (291-292 and 303-305)	0.1	0.0-0.2	0.1	0.0-0.1	2.1	1.8-2.4	0.7	0.6-0.7
Anxiodepressive disorders (296 - 300, 311, 313)	0.9	0.7-1.1	0.5	0.4-0.5	34.2	33.1-35.4	7.7	7.6-7.7

Table 3   Prevalence of concomitant disease for persons with or without diagnosed ASD in the first year of life or in their lifetime, 1- to 17-year-olds, Québec, 2014-2015 (continued)

	First year of life				During lifetime			
Concomitant diseases (ICD-9 codes)	**With ASD** (n=16 940)		**Without ASD** (n=1 447 660)		**With ASD** (n=16 940)		**Without ASD** (n=1 447 660)	
	%	99% C.I.	(%)	99% C.I.	(%)	99% C.I.	(%)	99% C.I.
Anxiety disorders (300, 313)	0.8	0.6-1.0	0.4	0.4-0.4	32.6	31.5-33.8	7.1	7.1-7.2
Reactive disorders (308, 309)	0.2	0.1-0.3	0.1	0.1-0.1	16.9	16.1-17.7	3.3	3.2-3.3
Schizophrenia (295)	0.0	0.0-0.0	0.0	0.0-0.0	1.1	0.9-1.3	0.1	0.1-0.1
Behavioural disorders (301, 302, 312)	0.6	0.4-0.7	0.2	0.2-0.3	13.2	12.5-13.9	2.2	2.1-2.2
Personality disorders (301)	0.1	0.0-0.1	0.0	0.0-0.0	3.9	3.5-4.3	0.5	0.5-0.5
Attention deficit hyperactivity disorder (314)	0.6	0.4-0.8	0.2	0.2-0.2	42.0	40.7-43.3	9.3	9.2-9.3
Delayed development (315 and 317-319)	5.3	4.8-5.8	1.4	1.4-1.4	57.1	55.6-58.6	8.4	8.3-8.4
Mental retardation (317-319)	0.2	0.1-0.3	0.0	0.0-0.0	6.0	5.5-6.5	0.2	0.2-0.2
Inflammatory CNS diseases (320-327)	0.5	0.4-0.7	0.3	0.3-0.3	1.4	1.2-1.7	0.7	0.7-0.7
Hereditary and degenerative CNS disorder (330-337)	0.8	0.6-1.0	0.2	0.2-0.2	2.5	2.2-2.8	0.6	0.5-0.6
Other CNS diseases and syndromes (340-349)	2.4	2.1-2.7	0.6	0.6-0.6	14.8	14.1-15.6	4.5	4.5-4.5
Epilepsy (345)	1.3	1.1-1.5	0.3	0.3-0.3	8.4	7.9-9.0	1.3	1.3-1.3
Diseases of the peripheral nervous system (350-359)	1.0	0.8-1.3	0.2	0.2-0.3	4.5	4.1-4.9	0.9	0.9-1.0

Table 3   **Prevalence of concomitant disease for persons with or without diagnosed ASD in the first year of life or in their lifetime, 1- to 17-year-olds, Québec, 2014-2015 (continued)**

Concomitant diseases (ICD-9 codes)	First year of life				During lifetime			
	With ASD (n=16 940)		Without ASD (n=1 447 660)		With ASD (n=16 940)		Without ASD (n=1 447 660)	
	%	99% C.I.	(%)	99% C.I.	(%)	99% C.I.	(%)	99% C.I.
Diseases of the eye and its appendages (360-379)	15.1	14.4-15.9	9.9	9.9-10.0	42.9	41.6-44.2	27.9	27.8-28.0
Diseases of the ear and mastoid process (380-389)	30.0	28.9-31.1	27.8	27.7-27.9	83.1	81.3-84.9	69.6	69.4-69.8
Diseases of the circulatory system (390-459)	4.9	4.4-5.3	2.6	2.6-2.7	14.3	13.5-15.0	7.7	7.6-7.7
Diseases of the respiratory system (460-519)	56.9	55.4-58.4	51.3	51.2-51.5	92.7	90.8-94.6	84.0	83.8-84.2
Diseases of the digestive system (520-579)	28.3	27.2-29.3	20.2	20.1-20.3	63.3	61.7-64.9	45.5	45.3-45.6
Diseases of the genitourinary system (580-629)	11.3	10.7-12.0	6.8	6.8-6.9	38.4	37.2-39.6	28.1	28.0-28.2
Congenital abnormalities (740-759)	20.7	19.8-21.6	13.6	13.5-13.7	34.1	32.9-35.3	20.1	20.0-20.2
Other congenital abnormalities of the nervous system (742)	1.8	1.5-2.1	0.5	0.5-0.5	3.7	3.4-4.1	0.7	0.7-0.7
Down syndrome (758.0)	0.8	0.7-1.0	0.5	0.5-0.5	2.7	2.3-3.0	0.7	0.7-0.7
Perinatal disorders (764-779)	50.1	48.7-51.5	44.2	44.1-44.4	51.5	50.1-52.9	44.9	44.8-45.1
Trauma (800-999)	15.2	14.4-16.0	11.7	11.6-11.8	69.0	67.4-70.7	55.5	55.3-55.6

3.5 Number of medical consultations for children with ASD

Table 4 presents data for the population of Québec, aged 1 to 24 years, who have consulted a physician at least once in 2014-2015. It shows the number and the reasons for the consultations for persons with or without ASD. A person with ASD seems to receive, on average, two times more medical procedures than a person without ASD (5.8 versus 2.7). In addition, the number of consultations for mental health reasons is greater among those with ASD compared to those without ASD (2.3 versus 0.2).

Table 4 **Number of medical consultations for persons aged 1 to 24 years with or without diagnosed ASD in Québec in 2014-2015**

	Persons with ASD (n = 22 100)	Persons without ASD (n = 2 162 950)
Total number of consultations	127 270	5 761 070
Average number of consultations per patient	5.8	2.7
Total number of consultations for mental health reasons	50 900	532 755
Average number of consultations for mental health reasons per patient	2.3	0.2
Total number of consultations for reasons other than mental health	76 375	5 228 310
Average number of consultations for reasons other than mental health per patient	3.5	2.4

3.6 Profile of use of health services

Table 5 shows the proportion of incident cases according to age and to the specialization of the phycisian. Up to the age of 14, pediatricians make the majority of first diagnoses of ASD followed by psychiatrists (between 5 and 14 years old). After the age of 15, this tendency is reversed.

Table 5   **Proportion of incident cases according to age and the specialization of the doctor making a first diagnosis, Québec, 2014-2015**

Age group (Years)	Specialization of doctor who first diagnosed ASD				
	Psychiatrist	Pediatrician	Family physician	Other specialists	**Total**
	n (%)	**n (%)**	**n (%)**	**n (%)**	**n (%)**
01-04	75 (8.2)	644 (70.2)	123 (13.4)	76 (8.3)	918 (100.0)
05-09	221 (20.1)	652 (59.3)	182 (16.6)	45 (4.1)	1 100 (100.0)
10-14	188 (35.7)	259 (49.2)	67 (12.7)	13 (2.5)	527 (100.0)
15-17	104 (48.8)	69 (3.4)	30 (14.1)	10 (4.7)	213 (100.0)
18-24	97 (51.6)	15 (8.0)	66 (35.1)	10 (5.3)	188 (100.0)

3.7   Hierarchical profile of use of mental health services

The hierarchical profile of use of mental health services allows us to take into account the fact that the same person can consult different professionals or make use of different health services during the same period. The analysis focused on all of the people who had received a diagnosis of ASD during their lifetime. The profile of use identifies the patient based on whether they have been hospitalized, admitted to an emergency department, or consulted a family doctor, a psychiatrist, an outpatient pediatrician, or if they were seen at a clinic.

Table 6 shows the hierarchical use profile of medical health services for the year 2014-2015. For persons with ASD, in general, it appears that pediatricians and psychiatrists are consulted most often, followed by family doctors. This table also clearly shows that very few people with ASD are hospitalized and that less than 3% go to the emergency room for mental health reasons in a given year. People with ASD are more likely to use different medical services than people without ASD, particularly when it comes to reasons of mental health.

Figure 7 shows the hierarchical profile of use of mental health medical services of persons from 1-24 years old with ASD during the year 2014-2015 according to age group. It is clear that the types of professionals consulted change depending on the age of the person with ASD. As they age, people with ASD receive fewer services for mental health. Similarly, people without ASD are less likely to use mental health services.

Table 6 **Hierarchical profiles of use of mental health services for persons with or without diagnosed ASD, 1 to 24 years old, 2014-2015**

Place of Consultation for Mental Health	With ASD		Without ASD	
	Proportion	99% C.I.	Proportion	99% C.I.
Hospitalization	1.9	1.7-2.2	0.3	0.2-0.3
Residential care centres	1.2	1.0-1.4	0.1	0.1-0.1
Emergency	2.8	2.5-3.1	0.8	0.8-0.8
Outpatient psychiatrist	17.7	17.0-18.5	1.0	1.0-1.0
Outpatient pediatrician	22.3	21.5-23.1	3.0	2.9 - 3.0
Family doctor's office	9.2	8.7-9.7	4.0	4.0-4.0
Other specialized doctor	1.5	1.3-1.7	0.2	0.2 - 0.2
No mental health service	43.4	42.3-44.6	90.7	90.5-90.9

Figure 6 **Hierarchical profiles of use of medical services for mental health reasons for persons with diagnosed ASD, 1 to 24 years old, by age group, Québec, 2014-2015**
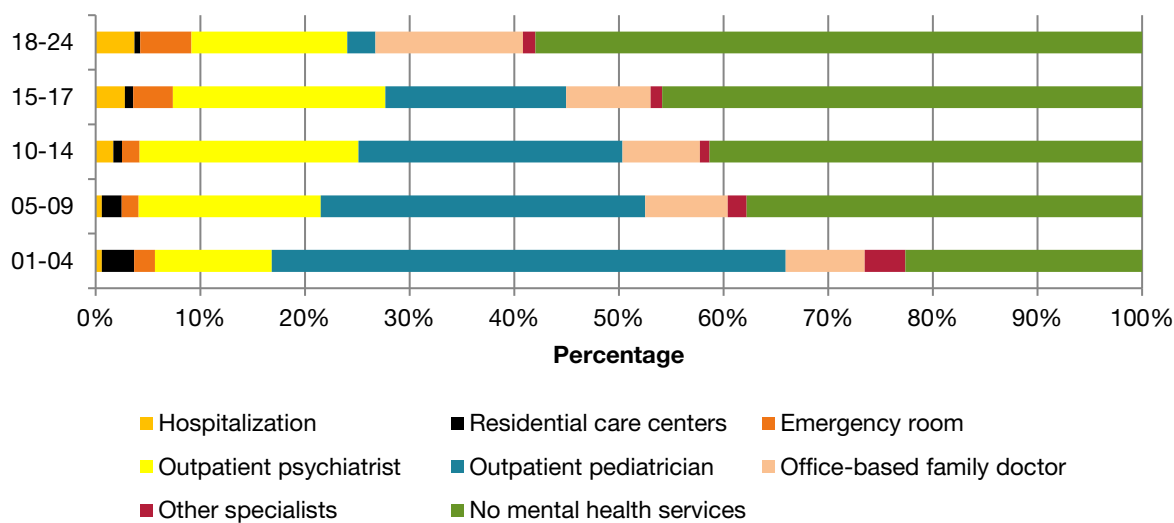
3.8   Measuring excess mortality

Table 7 shows 75 deaths occurring among persons aged 1-24 years with ASD for the period from 1996 to 2011. The death rate from suicide among persons with ASD is two times higher than for the general population without ASD. The death rate from other causes among persons with ASD is five times higher than for the general population without ASD.

Table 7   **Number and mortality rate by cause of death for persons aged 1 to 24 years with or without diagnosed ASD, Québec, 1996-2011**

Cause of death	Number and proportion of deaths		Mortality rate (Per 100 000 and 99% C.I.)	
	With ASD	Without ASD	With ASD	Without ASD
Suicide	10 (13%)	1 557 (15%)	9.9 (3.7-21.2)	4.1 (3.9-4.4)
Trauma	22 (29%)	5 229 (52%)	21.8 (11.7-36.8)	13.8 (13.3-14.3)
Other causes of death	43 (57%)	3,298 (33%)	42.6 (27.7-62.3)	8.7 (8.3-9.1)
Total	75 (100%)	10 084 (100%)	74.2 (54.0-99.3)	26.7 (26.0-27.3)

4   Discussion

The QICDSS shows that ASDs have risen steadily over the past decade, reaching a lifetime prevalence of 12 per 1 000 persons aged 17 years and younger in 2014 to 2015. This matches with data observed in the literature (between 9 and 14 per 1 000) (Anagnostou et al., 2014; CDC, 2016). Compared with the CDC's data for 2012 (14.6 per 1 000), the QICDSS shows a slightly lower prevalence for children 8 years old (12.3 per 1 000 in 2012). The incidence rate follows the same growth trend over time and had reached 1.9 per 1 000 in 2014-2015 in Québec. The ratio of ASD between boys and girls, 4 boys per 1 girl, matches that of the literature. If we consider the recent trends in 2014-2015 for the first time a diagnosis is received, it is often made before the age of 5 and, in the great majority of cases, before the age of 10. The great majority of diagnoses of ASD are made by pediatricians and psychiatrists, either doctors specialized in child development or in the diagnosis of mental disorders.

The interregional differences in the prevalence of ASD observed in this report (Figure 3) can be explained by many factors such as a school organization or health services that cannot reach everyone in need or because of the socio-economic determinants that influence them (Lesage, 1996; Oswald et al., 2013). This is consistent with an Australian study that justified the low prevalence of ASD in rural areas by a lack of available services (Leonard et al., 2011). This gap between the regions could also be explained by the sensitization of the population to this problem that varies from one region to another, as well as the migration of families with an ASD child to access medical and school services. In 2014-2015, QICDSS and MEES counted 16 010 and 13 275 children aged 4 to 17, respectively, with a diagnosis of ASD. There are 2 735 more cases in the QICDSS data, which could be mostly mild cases (Asperger's, unspecified ASD) who do not receive services at school. The QICDSS and MEES data are remarkably similar for some regions, but very different for others (Figure 3). The rates reported by the QICDSS for Estrie, Bas-Saint-Laurent, and Outaouais are very high compared to those of the MEES. This underestimation of the TSA rate from the MEES data could be explained, among other things, by the use of a single source of data for the identification of cases, unlike the QICDSS, which is composed of several data files making it possible to record children not declared at MEES. The MEES data may not be exhaustive, and a number of cases are missing: 1) students who do not meet the three criteria of the MEES (the diagnostic assessment performed by qualified personnel, the disability and limitations resulting from the impairment or disorder, and the support measures put in place to mitigate the impairment); 2) students waiting for diagnosis; 3) students with dual diagnosis reported under another disorder code; 4) students not enrolled in a school on September 30, but present in the following months (moving, reclassification during the year, etc.); and 5) students enrolled in a private school.

Our work showed a linear relation between social disadvantage and ASD. The prevalence of ASD in underprivileged environments is greater than in affluent areas. The relationship is more complex with material disadvantage, indicating a slight U-shaped relationship. The high prevalence among children from economically well-off families could be attributed to the association of the increasing age of the parent with the risk of genetic abnormalities. Numerous researchers have reported a link between the increased age of parents and ASD (Gardener et al., 2009; Sandin et al., 2012). Gardener et al. (2009) estimated that an increase of five years in maternal age led to a 7% increase in the risk of autism in the child. In fact, parents of children in affluent areas with a high income tend to have children at a later age (due, among other things, to the fact that they are trying to finish their post-secondary studies before becoming parents) (Statistics Canada, 2009). It could also be argued that these better-educated parents are better able to identify the specialized medical and educational services available in the regions, so their children would be diagnosed earlier. This is consistent with the analysis made by Sun and his collaborators that upper-class parents express more concerns than

those in the lower classes (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2014). In addition, the increase in prevalence in underprivileged environments could be due to the fact that environmental factors (physical or social) would be more frequent in these environments, and thus explain, at least in part, this higher prevalence of ASD.

The review of concomitant diseases was examined in two stages, in the first year of life and over the course of life, and compared with the population without ASD. In general, the results indicate a higher prevalence of concomitant diseases among people with ASD when compared to the general population without ASD (Table 3). For purposes of comparison, many studies of ASD-related diseases corroborate the data in this report (Berenguer-Forner, Miranda-Casas, Pastor-Cerezuela, & Rosello-Miranda, 2015; Chakrabarti & Fombonne, 2005; Fombonne, 2003; Gurney et al., 2006; Kohane et al., 2012; Timonen-Soivio et al., 2015; van Steensel, Bogels, & Perrin, 2011; Woolfenden et al., 2012). The prevalence observed in people with and without ASD may vary by study.

The average number of medical visits among people with ASD is twice as high as in subjects without ASD, which is expected given the concomitant illnesses identified previously. This observation is comparable to the results of Gurney et al. (2006). In addition, people with ASD make greater use of medical mental health services and are hospitalized more often for mental health reasons than the general population. This was also expected given the higher rates of concomitant illnesses with different mental disorders previously identified. A review of the hierarchical profile of use of these mental health services also shows that the majority of people with ASD aged 1 to 24 are supported by outpatient psychiatrists and pediatricians, but once the patients reach adulthood, these specialized services for mental health purposes diminish and are provided by family physicians. This finding echoes the concern raised in the recent literature that the transition to adulthood is associated with a break in the continuity of care provided by the health system and in the care of people with ASD (Kuhlthau, Warfield, Hurson, Delahaye, & Crossman, 2015; Watson, Parr, Joyce, May, & Le Couteur, 2011).

This report supports what is observed in the literature by showing that the proportion of deaths among people with ASD is twice as high as in the general population (Treating Autism, 2013; Woolfenden et al., 2012). However, it was not possible, given the small numbers, to enumerate and compare all of the specific causes of death.

Limitations

The QICDSS constitutes an inestimable source of information for the surveillance of ASDs, however it is not without limitations. As a linked medical and administrative data file, QICDSS is designed for administrative purposes, so some useful information may be missing (Blais et al., 2014). For example, the lack of information about services rendered outside Québec may represent a limit for interregional comparisons since it could result in underestimating prevalence measurements. This is the case, for example, in regions bordering Ontario or New Brunswick (Outaouais, Gaspésie-Îles-de-la-Madeleine, and Abitibi-Témiscamingue), where part of the population receives medical care in the neighbouring province. Although coverage of QICDSS is almost universal, it excludes Québec residents covered by federal health programs (refugee claimants, full-time members of the Canadian Forces, eligible veterans, members of the Royal Canadian Mounted Police, and inmates of federal penitentiaries). QICDSS does not identify eligible persons who have been seen by a salaried or contracted doctor (who does not code the patients' diagnoses), those who have sought health care provided by a professional other than a physician (in the community or private clinic or in the school environment), those who used health services without receiving a diagnostic code for relevant mental illness, and those who did not use health services at all.

In addition, there has been no validation study for ASD, but there are studies showing that, in general, the diagnosis recorded in the medical file corresponds very well to that recorded for the administrative databases for other diseases in Québec (Jean et al., 2012; Ouhoummane, 2010).

5   Conclusion

This report confirms that diagnosed ASDs have risen steadily in terms of prevalence and incidence and that they vary considerably across regions. It also demonstrates the QICDSS's capacity to identify concomitant diseases and their associated risk factors. Furthermore, the measurement of health services utilization (for mental and other health reasons) across the life trajectory of this disorder beginning in the first years of life may shed light on the specific needs of people with ASDs and on possible deficits in the service offer.

The results of this report have diverse implications. First of all, they provide an unprecedented view of ASD in Québec based on the new monitoring indicators developed under the framework of the QICDSS. In addition, they provide numerous paths for future research. These include exploring the etiology of ASD and the excess mortality in individuals with ASD, and identifying the social determinants of health that may contribute to the deterioration of the physical and mental health of people with ASD.

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