LAYING THE FOUNDATION FOR POLICY: MEASURING LOCAL PREVALENCE FOR AUTISM SPECTRUM DISORDER[†]

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SUMMARY

Claims have been made that families with children living with autism spectrum disorders (ASD) have been migrating to Alberta because of higher funding available for ASD supports compared to other provinces. The legitimacy of these claims, along with many others about the adequacy or inadequacy of funding for supporting persons living with ASD, has not been evaluated because we simply don't know how many people in Alberta are living with ASD. Typically in Canada, ASD prevalence is reported in national figures, based on international estimates. Canadian prevalence estimates for ASD are needed. With no national surveillance system in place, national estimates are difficult to determine. In addition, such broad measurements are problematic as they may not adequately inform the service delivery needs for specific jurisdictions.

A new study shows that 1,711, or 1 in 94, school age children in the Calgary region have an ASD diagnosis. As this number matches what is often reported for the national prevalence of ASD, it suggests that Alberta's relatively higher ASD funding is not inducing in-migration of families seeking better support. The data also show that the prevalence is higher in elementary-grade children, with a diagnosis in one of every 86 children. In the senior grades, there are significantly fewer students with ASD diagnoses, specifically within the Calgary Board of Education. There is no evident reason for diagnoses to seemingly dematerialize in the older grades. These students could be dropping out or choosing home-schooling in greater numbers. Possibly there has been an increase in prevalence.

These prevalence estimates help to inform the demand for special-needs services within the local school system. In addition, there is growing concern that upon graduation there is a "support cliff" resulting from a less systematized, less generous support system available for adults with neurodevelopmental disability. Families that need support for ASD face enough challenges; it is critical for policy-makers to be aware of the extent of the situation in their own jurisdiction so as to develop the right kinds of supports for these families.

INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition that is characterized by lifelong impairments in social relationships and communication, and repetitive, rigid behaviours.[1] Autism spectrum disorder is now the most commonly diagnosed neurological disorder in children.[2] Prevalence estimates provide vital information for policy-makers. Estimates guide the planning of resources required throughout the individual's lifespan, not only in the school and community starting during childhood, but also over the adolescent transition period (starting at age 12) and into adulthood. These estimates assist policy-makers in planning for school supports, employment programs, housing options and other programs essential to enhancing quality of life for individuals living with ASD and their families. Unfortunately, accurate estimates of ASD prevalence are difficult to acquire, and can be costly to undertake.[3] The widely quoted prevalence estimates for ASD are most often reported as national levels of prevalence which can mask the wide variation in prevalence levels for ASD across sub-national jurisdictions. For policy purposes, prevalence estimates would ideally be informative for the given geographical locales — such as the province, region or municipality — that is responsible for delivery of services.

Obtaining prevalence estimates of ASD is a policy objective that will assist policy-makers in planning for the costs required to support not only students with ASD, in regards to severity and level of cost (with severe children costing more), but also according to grade levels and changing demographics for the future needs of adults living with ASD. Without estimates that are relevant to specific jurisdictions, governments may be unprepared to manage the needs.

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[1] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. (Washington, D.C.: 2013). *The Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (DSM-IV-TR) definition of ASD is used throughout this report as this was the definition in use during the study period 2012-2013. Autism spectrum disorders were then described as a category of diagnoses that included autistic disorder, Asperger syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), Rett syndrome, and childhood disintegrative disorder. In May 2013, the next edition of the manual (DSM-5) was published by the American Psychiatric Association which now describes autism spectrum disorders without the above-mentioned sub-diagnosis and instead based on symptoms or history in 1) social communication/interaction; and 2) restricted and repetitive behaviours.

[2] E. Fombonne, "Epidemiology of pervasive developmental disorders," *Pediatric Research* 65, 6 (2009): 591-598.

[3] H. Ouellette-Kuntz et al., "National epidemiologic database for the study of autism in Canada (NEDSAC)," *Chronic Diseases and Injuries in Canada* 32, 2 (2012): 84-89.

For example, a recent report from Ontario by the People for Education notes that the Simcoe County area had a 17 per cent rise in special-needs students over the past five years, and consequently half of elementary principals in Ontario schools requested that parents of special-education-needs children have these students stay at home for all or some of the day, in part because there was not enough help for them.[4] Challenges in resource planning can also be seen in adult-housing issues, where unprepared community supports can result in a crisis for some. This situation arose in Ontario where parents of a severely autistic 19-year-old boy searched frantically for housing when their funding for his group home ran out. The family was depleted of resources and could no longer cope. Unfortunately, they were not the only ones to struggle as there was no flexibility in communities to create the response that people needed.[5]

In 2012, the Centers for Disease Control and Prevention (CDC) estimated that one in 88 children in the United States were diagnosed with ASD based on surveillance over a number of state-based sites.[6] The CDC now estimates the prevalence at one in 68,[7] with an increase of children living with ASD who have a higher IQ being diagnosed. Mandell and Lecavalier[8] question this most recent CDC estimate and raise concerns about wide variations in estimates between surveillance sites, noting that prevalence across sites ranged from one in 208 to one in 47. In particular, the aggregated site data are used to determine national prevalence, and this may be misleading. These huge variations in estimates between geographical locations create major challenges for policy-makers who must allocate resources based on state/provincial and municipal needs. Autism Ontario suggests that the best estimate of prevalence for Canada is about one in 94,[9] and the Autism Society of Canada states that prevalence in Canada is similar to that found in international studies.[10]

Currently, Canada lacks a national surveillance system that can provide estimates for geographic locales. For example, while prevalence estimates for ASD are reported for the United States and Canada, it is not clear whether these national-average estimates represent prevalence that would apply to Alberta or any other specific location. There are currently no prevalence estimates for Alberta and given the possibility that families with children living with ASD may migrate to Alberta for higher levels of funding,[11] a better understanding of local estimates is essential.

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[4] CTV News, "Special-needs students often asked to stay home from school," April 28, 2014, http://barrie.ctvnews.ca/mobile/special-needs-students-often-asked-to-stay-home-from-school-report-1.1796068.

[5] Laurie Monsebraaten, "Frantic Parents Search for Housing for Severely Autistic Son," *Toronto Star*, Sept. 22, 2012, http://www.thestar.com/news/gta/2012/09/22/frantic_parents_search_for_housing_for_severely_autistic_son.html.

[6] Centers for Disease Control and Prevention (CDC), "Prevalence of autism spectrum disorders – autism and developmental disabilities monitoring network, 14 sites, United States, 2008," *MMWR Surveillance Summaries* 61, 3 (2012): 1-19.

[7] Centers for Disease Control and Prevention (CDC), "Prevalence of autism disorder among children 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2010," *MMWR Surveillance Summaries* 63, 2 (2014): 1-21.

[8] D. Mandell and L. Lecavalier, "Should We Believe The Centers for Disease Control and Prevention's Autism Spectrum Disorder Estimates?" *Autism* 18, 5 (2014): 482-484.

[9] Autism Ontario: What is the best estimate of prevalence of autism in Canada? http://autismontario.novosolutions.net/default.asp?id=133.

[10] M. Orsini, "Autism, neurodiversity and the welfare state: The challenges of accommodating neurological difference," *Canadian Journal of Political Science* 45, 4 (2012): 805-827.

[11] Library of Parliament, "Provincial and territorial funding programs for autism therapy" (Parliamentary Information and Research Service: 2006).

With this purpose in mind, the objective of this study was to use school records from Calgary, Alta. and the surrounding area to undertake a census of the number of students by grade level living with ASD in this geographical region. School boards were considered to be a suitable resource for this study of ASD-prevalence data as schools generally are universally accessed by all children five to 17 years of age, including children with ASD. Accordingly, school board records constitute a complete and comprehensive one-source dataset within this jurisdiction for generating population-based ASD diagnosis at a community level. Additionally, school board representatives were supportive of the study and willing to share data that could be useful for planning and programming purposes. Although there were limitations in the data collection process, described at the end of this report, we estimate that approximately 91 per cent[12] of all children enrolled in schools for Calgary and area were included in this school census.

Results show that across grades 1 through 12 in the 2012/2013 school year, there were 1,711 students with ASD, which produces an overall prevalence of one in 94 children. This estimated prevalence for Calgary and area is similar to the average for Canada, as calculated by Autism Ontario, but is significantly less than the one in 68 average most recently reported for the U.S. by the CDC.[13] One surprising finding was that there were fewer children with ASD (significantly so) in the senior grades than in the elementary and junior grades. However, when the prevalence is calculated for elementary-grade children only, the result is one in 86. In each grade year (grades 1–12), there are between 115 and 163 children with ASD, with the average being approximately 140 children with ASD per year "graduating" to adult service programs in Calgary and the surrounding area. School boards and programs for supporting children and adults with ASD (in Alberta, for example, the Family Support for Children with Disabilities program and the Persons with Developmental Disabilities program) should expect these numbers of children in the system.

BACKGROUND ON THE CHALLENGE OF ACCURATE ASD SURVEILLANCE

Accurate estimates of ASD prevalence are a challenge to obtain yet essential to assist clinicians and policy-makers in planning for current and future needs of individuals and families.[14] With questions now arising about the accuracy of applying national estimates to specific geographical areas,[15] we consider the use of school records as an effective method to collect data. Although one-source records may not be considered the gold standard of surveillance, they may be a reasonable way to collect data for provincial policy-planning purposes.

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[12] In this study, six of the 38 independent/private/charter schools were included. We were not able to capture all of the 38 Calgary-and-area independent/private or charter school children. According to Alberta Education, the total number of children attending these schools in the area surveyed is approximately 16,444. We estimate that we counted 91 per cent of all children enrolled in all schools in the geographical area surveyed. This percentage does not include home-schooled children, as we were not able to capture any home-schooled children. Parents of home-schooled children in Alberta may join any school board in Alberta and it was not feasible to survey every Alberta school board in this study.

[13] CDC, "Prevalence" (2014).

[14] C.J. Newschaffer and L.K. Curran, "Autism: an emerging public health problem," *Public Health Reports* 118, 5 (2003): 393-399.

[15] Mandell and Lecavalier, "Should We."

Estimates of prevalence have risen dramatically over the past several decades.[16] The CDC estimates a 64 per cent and 123 per cent rise in prevalence since 2006 and 2002 respectively in the United States.[17] Over the past 30 years, ASD is estimated to have risen 600 per cent.[18] Canadian researchers, using the National Epidemiological Database for the Study of Autism in Canada (NEDSAC), estimate that the recent annual increase in prevalence across three regions in Canada (Newfoundland and Labrador, Prince Edward Island and Southeastern Ontario) ranged from 9.7 per cent to 14.6 per cent.[19]

The reason for the dramatic rise is uncertain. Researchers are not sure if it is a true rise in incidence, a result of changing diagnostic criteria and awareness, or a combination of these two explanations.[20] There are other factors that may also play a role in the rise, such as: inaccurate diagnosis due to lack of professional training and different diagnostic measures used; differing research methodologies (use of registry databases, retrospective accounts, telephone interviews and surveys); ages of children; environmental components; cultural differences; country studied; and previously undetected cases.[21] As well, within sub-national jurisdictions like Canadian provinces, it is not clear how much of a change in reported prevalence over time results from interprovincial migration,[22] which could be induced by cross-province differences in public funding for ASD services.

One of the major challenges in surveillance is the variability that exists in surveillance methods used to estimate ASD prevalence; each different method has benefits and limitations. Nonkin Avchen and colleagues[23] summarized four surveillance methods typically used and the limitations of each approach. The methods include: clinical screening and comprehensive clinical evaluation; surveys; service registries and administrative databases; and multi-record reviews of health and education records.

Clinical screening and comprehensive clinical evaluations rely on an unbiased professional approach, adequate sample size, location and infrastructure.[24] However, there are many challenges to obtaining an accurate diagnosis, including: changing diagnostic criteria, a wide range of functional ability, and varied presentation of co-morbidity for individuals living with ASD. An example of the challenge in obtaining an accurate understanding of severity was

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[16] E. Fombonne, "Epidemiological surveys of autism and other pervasive developmental disorders: An update," *Journal of Autism and Developmental Disorders* 33 (2003): 365-82; E. Fombonne, "The changing epidemiology of autism," *Journal of Applied Research in Intellectual Disabilities* 18 (2005): 281-294; J. Pinborough-Zimmerman et al., "Changes in the administrative prevalence of autism spectrum disorders: contributions of special education and health from 2002-2008," *Journal of Autism and Developmental Disorders* 42 (2012): 521-530.

[17] CDC, "Prevalence" (2012).

[18] J.J. Cannell, "Autism, will vitamin D treat core symptoms?" *Medical Hypotheses* 81 (2013): 195-198.

[19] H. Ouellette-Kuntz et al., "The changing prevalence of autism in three regions of Canada," *Journal of Autism and Developmental Disorders* 44 (2014): 120-136.

[20] G. Russell, "The rise and rise of the autism diagnosis," *Autism* 2, 1 (2012): 1000e104.

[21] J.L. Matson and A.M. Kozlowski, "The increasing prevalence of autism spectrum disorders," *Research in Autism Spectrum Disorders* 5 (2011): 418-425; J.G. Williams, J. P. Higgins, and C.E. Brayne, "Systematic review of prevalence studies of autism spectrum disorders," *Archives of Disease in Childhood* 91 (2006): 8-15.

[22] Ouellette-Kuntz et al., "The changing."

[23] R. Nonkin Avchen et al. "Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders," *Journal of Autism and Developmental Disorders* 41 (2011): 227-236.

[24] ibid.

noted by Edelson.[25] In a review of 215 articles from 1937 to 2003 for individuals with autism and intellectual disability (ID), it was found that a diagnosis of ID was based on a range of adaptive scales rather than appropriate cognitive-functioning measures. Variations in diagnostic tools used, professional training standards and changes in diagnostic criteria make the standardizing of ASD diagnosis challenging.

Survey methods often rely on parental reports and may use inadequate sample sizes.[26] For example, the responses from the National Survey of Children's Health in 2007, used by American researchers to better understand ASD, considered a child to have ASD if the parent reported that a physician or professional had given a diagnosis,[27] and not based on the actual medical report.

Service registries and administrative databases often have large sample sizes but they can be problematic as they only capture those individuals receiving services or those with specific codes representing a certain diagnosis.[28] Dodds and colleagues showed that there was some inaccuracy when identifying an ASD diagnosis using a large database. These researchers aimed to determine the accuracy of health databases. Results showed that the sensitivity of administrative databases based on an ASD code was 62.5 per cent. As such, these authors conclude that administrative health databases could be a cost-effective way to conduct ASD surveillance; however, more research was needed to improve accuracy and sensitivity. In Canada, administrative data is only feasible for estimating prevalence where data sets can be linked, and few provinces or territories have the infrastructure to use this as a surveillance method.[29]

Multi-record reviews are labour intensive, but they may increase accuracy. In the United States, the Autism Developmental Disabilities Monitoring (ADDM) Network collects prevalence data through the use of records-based surveillance systems. The ADDM Network monitors 14 sites across the United States using a records-review approach. Researchers with the ADDM Network in the United States use a two-step approach to data collection. First, multiple-source records (health and education records) are reviewed using eligibility classifications in special education or the International Classification of Diseases billing codes. Triggers in the records, such as certain behaviours, are also noted and these records are pulled for review. In the second step, records are reviewed for a diagnosis by trained clinicians using a coding scheme based on DSM-IV-TR diagnostic criteria.[30] Data are extracted from health and education records and reviewed by clinicians who assign a case status.[31] Researchers using multi-record reviews of

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[25] M.G. Edelson, "Are the majority of children with autism mentally retarded? A systematic evaluation of the data," *Focus on Autism and Other Developmental Disabilities* 21, 2 (2006): 66-83.

[26] Nonkin Avchen et al. "Evaluation."

[27] M.D. Kogan et al., "Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007," *Pediatrics* 124, 5 (2009): 1395-403.

[28] Nonkin Avchen et al. "Evaluation."

[29] Ouellette-Kuntz et al., "National."

[30] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. Text Revision (Washington, DC: 2000).

[31] CDC, "Prevalence" (2012).

both health and education records from sites in Utah found that prevalence in this state was one in 77, and concluded that across study years and age groups the rates were higher when health and school records were combined, as some children who had a health diagnosis did not have an ASD special-education code.[32]

School records (one-source record reviews) have been used by researchers in the past to examine ASD-related issues, but Nonkin Avchen and colleagues[33] note that the use of records-based surveillance systems can also be problematic, as these systems can have low diagnostic sensitivity and may yield conservative estimates. In Canada, Coo and colleagues[34] used school records to examine trends in the assignment of special education codes used in British Columbia. Diagnostic substitution, switching from a classification other than autism to autism over a period of time, accounted for at least one-third of the increase of autism prevalence in schools during the study period. In Montreal, Fombonne and colleagues[35] used school records to examine the trends between the diagnosis of pervasive developmental disorders and thimerosal exposure and found that exposure to thimerosal was unrelated to the increasing prevalence of pervasive developmental disorders. The authors observed that the prevalence in their study was consistent with recent surveys from other countries, as was the pattern of subtypes and gender. The authors were surprised by the accuracy of their prevalence estimate using school records because sole-record sources typically underestimate prevalence.

In the U.S., as mentioned above, school records are one of the data sources used by the CDC across a number of state-based ADDM Network sites. For sites that had access to school records, information about eligibility categories showed a wide variation in how children were coded in the primary autism-eligibility category. Among students with ASD who were receiving special education services in school, the proportion of ASD students with a primary-eligibility category of autism ranged from 30 per cent in Colorado to 69 per cent in Maryland. The variation in classification of primary autism may be due to the way that each state classified autism for special-education purposes. For example, at some ADDM Network sites, autism was a subcategory of physical disability, while at other sites autism was categorized as a speech and language impairment.[36] Internationally, researchers from the Netherlands used records of school children to determine prevalence. The researchers found higher rates of ASD in areas where there was work that attracted individuals with high skill levels in information technology (IT) and their families. A number of reasons for higher rates in that region could be the possibility of over-diagnosis in higher-prevalence areas, increased awareness about autism in parents and professionals, and under-diagnosis in the lower-prevalence regions.[37]

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[32] Pinborough-Zimmerman et al., "Changes."

[33] Nonkin Avchen et al. "Evaluation."

[34] H. Coo et al., "Trends in autism prevalence: diagnostic substitution revisited," *Journal of Autism and Developmental Disorders* 38 (2008): 1036-1046.

[35] E. Fombonne et al., "Pervasive developmental disorders in Montreal, Quebec, Canada: prevalence and links with immunizations," *Pediatrics* 118, 1 (2006): 139- 150.

[36] CDC, "Prevalence" (2014).

[37] M. Roelfsema et al. "Are autism spectrum conditions more prevalent in an information-technology region? A school-based study of three regions in the Netherlands," *Journal of Autism and Developmental Disorders* 42 (2012): 734-739.

USING SCHOOL RECORDS TO ESTIMATE PREVALENCE IN CALGARY AND THE SURROUNDING AREA

The population of children and adolescents investigated in this study resided in Calgary and the surrounding municipalities of Airdrie, Cochrane and several other smaller communities that together have a total population of approximately 1.2 million people.[38] Calgary is the largest city in Alberta. Calgary's economy has developed around the oil and gas industry and Calgary has the second-most corporate head offices among Canadian cities. Calgary's strong labour market over the past 20 years has resulted in Calgary having high personal and family incomes, low unemployment and high net migration in comparison to other Canadian cities. Calgary has a relatively young population in comparison to other Canadian cities due to the energy boom and high levels of in-migration.[39]

In this study, the participating districts/ boards and independent, private or charter schools included: a) the Calgary Board of Education (CBE), serving the public district for those living within the Calgary city limits; b) the Calgary Catholic School District (CCSD), a large Roman Catholic-based school board serving Calgary and the neighbouring communities of Airdrie, Chestermere and Cochrane; c) Rocky View Schools, a public school district serving families in the municipalities surrounding Calgary, specifically Airdrie, Chestermere, Crossfield, Cochrane, and the district of Rocky View; d) six schools from the French school district within Calgary; and e) six independent schools in Calgary.[40]

In Alberta, children who need supplemental educational supports and school funding for special-education programming within the classroom are given a special-education code.[41] These codes are divided into two categories using the Alberta government's Special Education Coding Criteria, 2012/2013: mild/moderate and severe. Specific numeric codes are used for students with a disability to assign levels of required support. For example, code 44 captures severe physical or medical disability, including ASD when the student's functional level is severe and they require extensive adult assistance and modifications to the learning environment. Codes for mild or moderate disability use numbers in the 50 range. For example, code 51 describes a student with a mild cognitive disability who has an IQ in the range of 50 to 75, plus or minus five, an adaptive-behaviour score equivalent to the mildly delayed level on an adaptive-behaviour scale, and demonstrates delay in most academic subjects and social behaviours compared to his or her same-age peers. The assignment of special-education codes is audited by Alberta Education to ensure that children are coded correctly and receive the appropriate level of support.

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[38] Statistics Canada, "Focus on Geography, Series 2011," http://www12.statcan.gc.ca/census-recensement/2011/as-sa/fogs-spg/Facts-cma-eng.cfm?LANG=Eng&GK=CMA&GC=825.

[39] C. Noble and C. Selinger, "Calgary Affordable Housing Needs Assessment" (Calgary, Alta.: The City of Calgary, Office of Land Service and Housing, 2012), http://www.calgary.ca/CS/OLSH/Documents/Affordable-housing/Housing%20Needs%20Assessment%20June%202012.pdf?noredirect=1.

[40] The independent schools included: Calgary Quest School, Renfrew Educational Services, Janus Academy, Providence, Third Academy and Foothills Academy. These six independent schools primarily serve children and adolescents who have special needs and developmental concerns in a variety of different areas (e.g., cognitive, physical, sensory, emotional, behavioural, medical, and/or social). Providence school numbers were excluded on analysis as children enrolled were only from Early Childhood Services and kindergarten levels.

[41] This study received ethical approval from the Conjoint Faculties Research Ethics Board at the University of Calgary, Canada (CFREB ID #6987).

In the Alberta school system, a diagnosis of ASD requires proof from a registered health professional (i.e., psychiatrist, psychologist, pediatrician or physician). The school board does not typically reconfirm the diagnosis upon registration of the student through a standardized method and so relies on previous reports from these professionals. Parental reports alone are not an accepted confirmation of ASD.

To collect the data in this study, each of the large boards assigned one person to collect data for all schools served by that board, and for the independent private schools that participated, each school designated one person for their school to collect data for that school.[42] Designates were given instructions to pull all cases of ASD according to the DSM-IV categories. Based on their respective recording systems, each board and school identified the children with an ASD diagnosis in a different manner. The CBE and Rocky View board designates used the special-education codes to search all codes that might capture a student with ASD and then reviewed all coded records for those who had an ASD diagnosis on record. The CCSD had an electronic database with a field for diagnosis, and so the representative queried the database for ASD first and pulled all cases from that field. For the independent and private schools, where smaller numbers of children were enrolled, the key designate at that school confirmed each child's diagnosis by reviewing the records manually. All board and independent school data-collection designates reviewed registration records of all children enrolled in Early Childhood Services (ECS) /kindergarten up to Grade 12 in the school year 2012–2013, and compiled the data into a Microsoft Excel spreadsheet.

Our analysis excluded children in ECS or kindergarten, as some school boards had specialized programs for children in those grades with special needs while others did not. We gathered overall school board student counts by grade from the provincial Ministry of Education's enrollment report for the 2012–2013 school year.[43] We broke down the number of students by ASD diagnosis (autistic disorder, Asperger disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), Rett syndrome, and childhood disintegrative disorder), from grades 1 through 12, according to special-education code (severe or mild/moderate) and sex.

STUDY RESULTS

The total number of children registered in Calgary and the surrounding area by individual school boards, the number who had an ASD diagnosis on record, and the breakdown within each board of specific ASD subcategory are shown in Table 1.[44] A total of 160,904 children were counted in school districts in Calgary and area from Grade 1 to Grade 12 in the 2012–2013 year. Of this total, 1,711 children had an ASD diagnosis on their school record, making the prevalence of ASD 1,711 in 160,904, or one in 94, across all school boards. The

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[42] Personnel affiliated with each of the school boards were approached in person to participate in the school census study and were provided with a description of the study, what was involved in participating, and the risks and benefits of participating. For participating, the larger boards were offered funding towards a support person to offset any extra resources that may have been required as a result of time required to review school records.

[43] Alberta Education, "Student Population by Grade, Year, and Authority, Alberta: 2012/2013 School Year."

[44] The individual schools have been collapsed into one category titled "other," to prevent identification of single students.

prevalence rate differs noticeably by school board. We measure it as one in 97 in the CBE, one in 116 in the CCSD and one in 120 in Rocky View. While the "other" category had a one in 11 prevalence rate, this prevalence is likely high due to some of the schools being tailored to children with ASD.

TABLE 1:   INDIVIDUAL SCHOOL COUNTS AND DIAGNOSTIC CATEGORY

	School Boards				
	CBE	CCSD	Rocky View	Other	Total
Total number of children enrolled	97,293	44,774	16,868	1,969	160,904
Autistic disorder	570	223	72	132	997
Asperger disorder	209	79	36	20	344
Other	225	84	32	29	370
Total Diagnosed	**1,004**	**386**	**140**	**181**	**1,711**

Of the children with an ASD diagnosis, the ratio of boys to girls for all schools combined in the Calgary and the surrounding area was 5.2:1 (Table 2). The CBE had the highest ratio of boys to girls (5.9:1), followed by CCSD (5.3:1), higher than the average of all independent schools (3.6:1) and of Rocky View schools (3.4:1).

TABLE 2:   ASD DIAGNOSIS BY SEX AND BY SCHOOL BOARD

	School Boards				
	CBE	CCSD	Rocky View	Other	Total
Male	859	325	108	142	1,434
Female	145	61	32	39	277
Ratio M:F	**5.9:1**	**5.3:1**	**3.4:1**	**3.6:1**	**5.2:1**

The total count of children by diagnostic category for Calgary and surrounding area is shown in Table 3. Of the 1,711 children who had an ASD diagnosis on record, 997 children (58.27 per cent) had autistic disorder (or autism), 344 (20.11 per cent) had Asperger disorder, and 370 students (21.62 per cent) had a diagnosis of PDD-NOS, childhood disintegrative disorder, or Rett syndrome.[45]

TABLE 3:   TOTAL COUNT IN ALL SCHOOLS BY DIAGNOSTIC CATEGORY

Diagnostic Category	Total Number	Per Cent
Autistic disorder	997	58.27%
Asperger disorder	344	20.11%
Other	370	21.62%
Total	**1,711**	**100.00%**

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[45] These categories were collapsed into "other" to prevent the identification of the small number of children with Rett syndrome or childhood disintegrative disorder. The large majority had a diagnosis of PDD-NOS.

Table 4 shows the distribution of children with ASD by grade level. When grouped by grade into elementary (grades 1 to 6), junior high (grades 7 to 9), and senior high (grades 10 to 12), the prevalence shows a significant decrease in cases of ASD for senior grades in comparison to both elementary and junior grades (Table 5). The prevalence for senior students is statistically lower than for junior or elementary students (tested with a Z-test for proportions and a five per cent significance rate, which indicated that the prevalence for senior students is statistically lower). The drop in prevalence in senior grades appears to be specific to the CBE (Table 4).

The Alberta Education Severity Code captures the number of children living with ASD who were considered to be mild/moderate or severe in an educational setting. Of the total number of children in the sample who had a diagnosis, 1,532 (89.54 per cent) were severe, 162 (9.47 per cent) were coded as mild/moderate, and 17 (0.99 per cent) were missing codes (Table 6). The Calgary School Board had the highest percentage of children considered severe (95.12 per cent) among the larger boards. Several of the independent schools served special-needs children and, as expected, had high proportions of students diagnosed with ASD who were severe.

TABLE 4:   DISTRIBUTION OF CHILDREN WITH ASD BY GRADE LEVEL

	School Boards				
	CBE	CCSD	Rocky View	Other	Total
Grade 1	83	37	9	18	147
Grade 2	83	35	12	22	152
Grade 3	101	35	18	9	163
Grade 4	90	27	10	19	146
Grade 5	87	33	11	22	153
Grade 6	77	26	11	20	134
Grade 7	90	21	11	6	128
Grade 8	85	38	9	10	142
Grade 9	79	37	10	18	144
Grade 10	75	29	12	14	130
Grade 11	64	25	14	12	115
Grade 12	90	43	13	11	157
Total	**1,004**	**386**	**140**	**181**	**1,711**

TABLE 5:   PREVALENCE OF AN ASD DIAGNOSIS BY AGE CATEGORY

Grade Level	Prevalence per 1,000	Cases Ratio
Elementary	11.61 *	1 in 86
Junior	11.11 *	1 in 90
Senior	8.88	1 in 113

* indicates statistically different from senior prevalence at five per cent significance

Severity	School Boards				
	CBE	CCSD	Rocky View	Other	Total
Severe	955 95.12%	347 89.90%	77 55.00%	153 84.53%	1,532 89.54%
Mild/Moderate	48 4.78%	38 9.84%	61 43.57%	15 8.29%	162 9.47%
Missing	1 0.10%	1 0.26%	2 1.43%	13 7.18%	17 0.99%
Total	1,004	386	140	181	1,711

DISCUSSION

This study presents the first ASD-prevalence estimate for an urban area of Alberta. The overall prevalence for all grades combined was significantly different than the prevalence quoted by the CDC.[46] In this study, the prevalence of ASD for all children enrolled in school was one in 94, while the CDC prevalence was one in 68 children based on data collected in 2014.[47] However, if we consider only the elementary grades (grades 1-6) the prevalence in this study is one in 86. For all grades, the diagnosis of ASD between males and females was 5.2:1. The CDC reports that the male-to-female ratios range varied widely across ADDM Network sites, from 2.7 in Utah to 7.2 in Alabama, but with all sites combined the ratio was 4.6 boys to one girl.[48] Fombonne[49] from the review of literature found the mean male to female ratio to be 4.2:1.

Our study found that of those with an ASD diagnosis, 58 per cent of individuals had a diagnosis of autistic disorder and 20 per cent were diagnosed with Asperger disorder (AD). Fombonne[50] in the review of 43 studies of prevalence literature of pervasive developmental disorders notes that the prevalence of Asperger disorder is much lower than autistic disorder and childhood disintegrative disorder is very rare. Fombonne[51] summarized the prevalence estimates for the whole spectrum in the 60-70/10,000 range (one in 167 to one in 142). Epidemiologic studies of Asperger disorder were much more difficult to find in the review and Fombonne's best estimate is that the ratio of AD is about one-third to one-quarter that of autism.[52]

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[46] CDC, "Prevalence" (2014).

[47] One in 94 is statistically different than the one in 68 reported by the CDC, using a 95 per cent confidence interval from about one in 99 to one in 90.

[48] CDC, "Prevalence" (2012).

[49] Fombonne, "Epidemiology."

[50] Ibid.

[51] Ibid.

[52] These diagnostic categories have been reclassified in the DSM-5.

For level of severity, our study found that 89 per cent of children with ASD were considered severe in an educational setting. This category is difficult to compare to the CDC results due to the fact that school boards code children as severe not only for severe cognitive delays (IQ of 30, plus or minus five), but also for severe delays in all or most areas of development, and for severe emotional or behavioural disorders (not necessarily IQ related). If one uses IQ alone as a measure of severity, the CDC estimates 38 per cent of individuals with ASD also meet the criteria for an intellectual disability (IQ less than or equal to 70),[53] but the CDC does not report on levels of severity based on functional ability or levels of support needed across the spectrum. Still, the percentage of individuals with an ASD diagnosis coded as severe (89 per cent) and in need of higher levels of support in an educational setting is much higher than 38 per cent — the prevalence of those with an IQ of 70 or less who often have lower functional ability. Brown and colleagues[54] completed a study of 97 families, that examined the parental perceived level of need with the level of their child's functional independence, coded as low, moderate or high. Families of children with high functional independence had lower unmet needs in comparison to families of children with moderate functional independence. Many factors contribute to a family's ability to cope, but the functional independence level of the child (or dependent adult) is essential in understanding parental-support needs.[55] If, in our study, the educational coding system reflects the level of a child's functional ability, then the high percentage of children with ASD coded as severe (89.54 per cent) in this study could also indicate that a high level of parental unmet-need exists.

A surprising finding is the significant difference between the senior grades compared to lower grades. This drop could reflect a true rise in prevalence for younger children over the past decade, a possibility noted by Canadian researchers.[56] However, the decreased numbers of children with ASD in senior grades was specific to the CBE and not seen in the two other largest boards. It is possible that the decreased numbers in senior grades reflects that students are leaving the CBE in senior grades, but it is not clear where they are going in Calgary as none of the other Calgary-area boards or schools showed a coincident increase in numbers. It is possible they are moving into home-schooling, where the numbers of children moved may not be seen through this study as parents can choose to be affiliated with any board in Alberta for home-schooling and all Alberta school boards were not part of the study. It is also possible that these students are dropping out of school. The United Way of Calgary and Area reported a large number of students in Calgary who do not complete high school on time, (one in four) where a portion of this group of students dropped out of school.[57] The United Way does not describe characteristics of those who are dropping out, so we are not able to determine how many students with ASD may be part of this group.

[53] CDC, "Prevalence" (2012).

[54] H.K. Brown et al., "Beyond an autism diagnosis: children's functional independence and parent's unmet needs," *Journal of Autism and Developmental Disorders* 41 (2011): 1291-1302.

[55] Brown et al., "Beyond."

[56] Ouellette-Kuntz et al., "The changing."

[57] United Way ,"Calgary leaders aim to cut dropout rate by 50 per cent over five years," Media Release, June 12, 2013, http://www.calgaryunitedway.org/main/images/Calgary%20leaders%20aim%20to%20cut%20dropout%20rate%20-%20June%2012%202013%20-%20Media%20Release.pdf.

The rise in numbers in the lower grades could be related to families coming to Alberta to access Alberta's higher levels of funding for early intervention of ASD. However, interprovincial migration patterns are complex and it would be misleading to attribute in-migration only to ASD service funding. Families may come to Alberta for a variety of reasons; in-migration for work opportunities is an example of one possible reason. As well, excellent funding for Early Childhood Services for ASD has been in place since that late 1990s in Alberta, so it would not be a compelling explanation for a recent increase in prevalence at younger ages. A hypothetical child with ASD born in 1996, diagnosed in 1998, and who moved to Alberta in 1998 for the funding, would be in Grade 12 at the time of this study, so one would expect to see in-migration impacting all grades in this study. Unfortunately, we are unable to make clear conclusions about the impact of migration on ASD prevalence in Alberta. We do note that the fact that as our prevalence estimate is at or below estimates for national-level ASD prevalence, it does not appear that relatively high levels of funding for ASD services has been influential for migration to Alberta for families with children with ASD.

It is quite possible that the rise in prevalence in the younger years is a combination of all the factors noted above, including changing diagnostic criteria and general increased ASD awareness.[58] Regardless of the reason for a rise in prevalence, the issue of how to manage the support needs of a growing demographic in an educational setting and beyond requires closer examination.

FUTURE DIRECTIONS

Our study shows that administrative coding information in school records provides estimates of ASD prevalence that reflect geographic areas and are comparable to national surveillance reports, as that found by Autism Ontario, at one in 94. This shows that school records can be used for surveillance of conditions such as ASD or attention deficit hyperactivity disorder (ADHD). These are high-prevalence conditions that, if followed in an organized way at the provincial level, would provide important information for policy-makers. The use of these records represents a feasible and pragmatic approach to surveillance that is not too burdensome to finance. Given the concerns noted by Mandell and Lecavalier[59] over the wide variations in prevalence between sites based on geography in the United States, pragmatic regional estimates may be of more use to policy planners than infrequent national estimates that use gold-standard surveillance practices. The ability to follow a demographic by grade level may also be useful for monitoring significant changes and on an individual level to observe delays in diagnosis or diagnostic substitution as discussed by Coo and colleagues.[60] School administrative coding offers an opportunity for conducting ongoing surveillance to support better planning and resourcing of school-based supports and potentially for evaluation of longer-term outcomes for interventions conducted in the schooling years.

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[58] Matson and Kozlowski, "The increasing."

[59] Mandell and Lecavalier, "Should We."

[60] Coo et al., "Trends."

Obviously an important future direction is to repeat the data collection reported here at regular intervals (i.e., yearly) and to do this for the rest of the province. Critically, funding commitments to conduct the data collection will need to be made that add to school board budgets rather than those that displace existing board funds for other purposes. As these data are of use and interest across at least three government departments in Alberta — Education, Human Services and Health — it would seem logical that the cost of the data collection be shared across these departments.

Another important future direction is to use the administrative records to define a population of Albertans with ASD to track beyond Grade 12. For example, efforts to determine if these individuals pursued post-secondary education or obtained employment and if they live independently or if they continue to live at home or in other supported environments would provide important information for lifespan policy directions. With this information it would be possible to evaluate current approaches or piloted approaches for changes in resources, programs and other interventions for children and adolescents with ASD in the school system and the possibility to assess their future needs as adults.

Finally, ASD typically presents with psychiatric co-morbidities, which adds to the heterogeneity of needs for supports amongst the ASD student population. Adding information on psychiatric co-morbidities would be useful for establishing what multidisciplinary supports would be helpful for improving life outcomes for students with ASD.

STUDY LIMITATIONS

One of the limitations associated with this study was the use of one type of record source (school records) as opposed to combined health and education records, which are considered to be a better estimate of true population prevalence. A second limitation was that we were unable to confirm that the same standards of diagnosis were used across clinicians. In Alberta, the formal identification of ASD in schools requires proof of diagnosis from a registered health professional (i.e., psychiatrist, psychologist, pediatrician or physician). The school boards do not reconfirm a diagnosis upon registration through a standardized method across boards. Third, we were unable to capture all of the independent, private and charter schools or the home-schooled children in Calgary and surrounding areas. Due to the large number of small independent, private and charter schools, it was not feasible to approach them all. A complete picture of all home-schooled children living in Calgary and the surrounding area was also not feasible, as parents who opt for home-schooling in Alberta may choose to be associated with any school board throughout the province, inside or outside of the Calgary region. It was not feasible to approach all school boards in Alberta to request a review of records for home-schooled children living only in Calgary and surrounding areas. We estimate that we were able to capture 90.8 per cent of school-age children in Calgary and area, not including home-schooled children. Regional prevalence in this study may be underestimated depending on the number of children with ASD who are home-schooled or are in private schools that were not included, and because of the use of one-source-records methodology.

CONCLUSION

Prevalence estimation has an important role in informing policy decision-making and resource allocation. With rapidly rising prevalence rates, there is added urgency to government policy discussions. However, prevalence estimates for ASD are often reported as national levels of prevalence, which can be difficult to adapt to individual jurisdictions. In contrast to these types of national estimates, this study provides the first local-prevalence estimate for ASD in Alberta. We report the local prevalence of ASD as one in 94 children across multiple school boards in the Calgary and surrounding region. These types of estimates of the number of children with ASD are critical for managing the needs of the ASD population, informing policy and planning for the cost required to support students, and streamlining resources required for school supports, employment programs and housing options. This study demonstrates a negotiated process of effectively working within and across school boards to access records of ASD, offering an alternate approach to determining an estimate of the regional prevalence of ASD.

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