Validating an administrative data-based case definition for identifying children and youth with autism spectrum disorder for surveillance purposes

Helen Coo, MSc,[1] Hélène Ouellette-Kuntz, PhD,[2] Marni Brownell, PhD,[3] Shahin Shooshtari, PhD,[4]
Ana Hanlon-Dearman, MD, MSc[5]

ABSTRACT

OBJECTIVES: To evaluate the sensitivity and positive predictive value (PPV) of administrative health and education data for identifying cases of autism spectrum disorder (ASD) in Manitoba, and to recommend a surveillance case definition.

METHODS: Four service providers abstracted information on children who had been clinically diagnosed with ASD ("sensitivity cohort"). That information was linked to Manitoba's administrative health and education data and records were extracted into the study dataset. Records were also included for children who had an administrative diagnosis of ASD but who were not part of the sensitivity cohort. Study packages were mailed to the parents of the latter group in order to verify their diagnostic status. The sensitivity and PPV of various case definitions were calculated.

RESULTS: Among the 1728 service provider-reported cases, 1532 had an administrative diagnosis of ASD. A total of 2414 children had an administrative diagnosis, of whom 882 were not part of the sensitivity cohort. The response to the mail-out was very poor (<3%). Accordingly, we calculated minimum PPVs. Our recommended surveillance case definitions are ≥1 physician claim (ICD-9-CM 299) or ≥1 "ASD" special education record (2–5 years of age), and ≥2 physician claims or ≥1 "ASD" special education record (6–14 years of age). The sensitivity ranged from 80% (95% CI: 77–83) to 88% (95% CI: 83–91) and the minimum PPV from 70% (95% CI: 67–73) to 78% (95% CI: 75–81) for these definitions.

CONCLUSION: This work advances the goal of establishing a cost-effective national surveillance system for ASD.

KEY WORDS: Autism spectrum disorder; surveillance; administrative data; validation studies; Manitoba; Manitoba Centre for Health Policy

La traduction du résumé se trouve à la fin de l'article.

The Public Health Agency of Canada (PHAC) is establishing an autism spectrum disorder (ASD) surveillance system in response to calls for data to inform programs and services for individuals and families living with ASD.[1] The use of administrative data for this purpose has not been comprehensively evaluated, although researchers in Nova Scotia examined the sensitivity and specificity of that province's administrative health data for identifying children with ASD.[2] The highest sensitivity observed was 69.3%. This illustrates one of the challenges of using administrative data for ASD surveillance: unlike chronic health conditions that are diagnosed by physicians and medically managed, ASD can be diagnosed by other types of professionals (e.g., psychologists), and utilization of services and supports (e.g., intensive behavioural intervention) are not generally captured in administrative health data.

Access to routinely collected education data, where available, would likely result in more complete case capture. The ease with which researchers from different regions can access education records, and link them with administrative health data, varies considerably. A few regions have well-established administrative data linkage infrastructures that facilitate this process. The Manitoba Centre for Health Policy's Population Health Research Data Repository ("Data Repository") is a national leader in this regard. Through data-sharing agreements, it holds numerous health and non-health datasets.[3] Encrypted personal health identification numbers (PHINs) are attached to person-level records in those datasets, which enable records to be accurately linked across datasets and years while maintaining confidentiality.[4]

Author Affiliations

1. Department of Public Health Sciences, Queen's University, Kingston, ON
2. Department of Public Health Sciences, Queen's University and Ongwanada, Kingston, ON
3. Department of Community Health Sciences, University of Manitoba and Manitoba Centre for Health Policy, Winnipeg, MB
4. Department of Community Health Sciences, University of Manitoba and St.Amant Research Center, Winnipeg, MB
5. Department of Pediatrics and Child Health, University of Manitoba, Winnipeg, MB

Correspondence: Dr. Hélène Ouellette-Kuntz, Department of Public Health Sciences, Queen's University, 191 Portsmouth Avenue, Kingston, ON K7M 8A6, Tel: 613-548-4417, ext. 1198, E-mail: helene.kuntz@queensu.ca

In this paper, we present and discuss the findings of work done on behalf of PHAC to evaluate the sensitivity and positive predictive value of Manitoba's administrative health and education data for identifying children and youth ("children") with ASD.

METHODS

Identification of clinically diagnosed cases of ASD

Four service providers, each of whose catchment area includes all of Manitoba, reviewed their files to identify children born between 1997 and 2009, inclusive, who had been diagnosed with ASD on or before December 31, 2011. The service providers included the Child Development Clinic, to which province-wide referrals for developmental assessment can be made up until a child's sixth birthday; St.Amant, which delivers Applied Behavioural Analysis services to children with ASD living anywhere in the province (except residents of First Nation reserves) if they are under the age of five years at the time of referral to the Early Learning Program, or if they apply as a new resident of Manitoba to the School Age Learning Program; the Manitoba Adolescent Treatment Centre, to which parents, caregivers, physicians and counsellors can refer children 3–18 years of age for assessment of behavioural concerns, and which also offers various intervention services for school-age children with ASD; and Children's disABILITY Services, which offers a variety of resources and supports to families who have a child under 18 years of age with a physical or developmental disability (with the exception of families living on First Nation reserves).

The case identification procedures are summarized in Table 1. Each service provider abstracted data into a spreadsheet provided by the research team, which was pre-populated with an agency number. Those data included child identifiers (name, date of birth, sex, most recent postal code of residence on file, and, where collected by the

service provider, the PHIN) and basic diagnostic information. Service providers were also instructed to assign a uniquely identifying number to each case identified ("client ID"). Staff members at each service provider performed the data abstraction.

Preparation of crosswalk files at Manitoba Health, Seniors and Active Living and linkage of de-identified diagnostic information with crosswalk files at Manitoba Centre for Health Policy

Once all the case data had been abstracted, service providers saved the information into two files. The first file contained the agency number, client IDs, and the child identifiers. This file was sent to Manitoba Health, Seniors and Active Living (MHSAL). There, the child identifiers were cross-referenced with MHSAL's Insurance Registry to verify that the abstracted PHINs were correct. Where PHINs had not been abstracted or were missing, the other identifiers were used to search the Insurance Registry and add PHINs to the file. Four crosswalk files (one for each service provider's data) were prepared, which contained encrypted PHINs, the agency number, and client IDs. These files were sent to the Manitoba Centre for Health Policy (MCHP).

The second file contained the agency number, client IDs, and de-identified diagnostic information. The service providers sent these files to MCHP. The diagnostic information was then linked to records in the crosswalk file by matching on the two elements common to both files: the agency number and the client ID. The resulting four files were then merged and multiple records for individuals identified by more than one service provider were combined into one record.

Creation of study dataset

The Research Registry housed in the Data Repository was used to identify children born from 1997 to 2009, inclusive, and to extract

Service provider	Scope of review	Case identification	Exclusion criteria
Children's disABILITY Services*	Individuals born 1997–2009 who were eligible for Children's disABILITY Services from April 1, 2009 to December 31, 2011	Search of "reason for eligibility" field in inFACT (IT system) for autism spectrum disorder (ASD)[†]	None
St.Amant	Individuals born 1997–2009 who received Applied Behavioural Analysis services[‡] through St.Amant's Early Learning (preschoolers) and School Age Programs at any time between January 1, 1998 and December 31, 2013	File review to identify individuals with a Verification of Autism Diagnosis form on file from a developmental pediatrician, psychologist or psychiatrist	Initially diagnosed with ASD after December 31, 2011
Manitoba Adolescent Treatment Centre	Individuals born 1997–2009 who presented for assessment or treatment at any time from January 1, 1998 to December 31, 2013	Automated search of all existing documentation for those diagnoses that fall within the autism spectrum; manual review of the clinical record to confirm the diagnosis and collect the diagnostic information required	Individuals residing outside Manitoba at time of assessment or treatment; no confirmed diagnosis of ASD on discharge; initially diagnosed with ASD after December 31, 2011
Child Development Clinic	Individuals born 1997–2009 who were diagnosed at the Child Development Clinic between January 1, 1998 and December 31, 2011	Review of billing sheets to identify individuals diagnosed with ASD; review of charts to confirm the diagnosis and collect the demographic and diagnostic information required	Individuals residing outside Manitoba at time of diagnosis

Table 1. Scope of chart/file review and case identification procedures

* Provides province-wide services to Manitoba children and youth under 18 years of age (except those living on First Nation reserves).
† Eligibility is based on a confirmed diagnosis of ASD made by a pediatrician, psychologist or psychiatrist. Children's disABILITY Services requests a copy of the assessment report. Statements such as "would appear to be consistent with a diagnosis of ASD" are not accepted as confirmed diagnoses and Children's disABILITY Services would request further assessment of those children.
‡ Available province-wide to all children on the autism spectrum (except those living on First Nation reserves) if they are under five years of age at the time of referral to the Early Learning Program, or, if they apply as a new resident of Manitoba to the School Age Learning Program, if they have participated in another intensive behavioural intervention.

information on their date of birth, sex, postal code, and whether the child was born in Manitoba. The file containing the de-identified diagnostic information for service provider-reported cases was linked to records for these births. The resulting file was then linked to records from January 1, 1997 to December 31, 2011 (the study period) that were searched and extracted from four administrative data sources at MCHP to identify those with an administrative diagnosis of ASD. A description of each data source, as well as the definitions of an administrative diagnosis of ASD, are provided in Table 2. Collectively, these definitions are referred to as "ASD codes". The date associated with each ASD code was also extracted, as were codes for other mental health conditions or developmental disorders recorded over the study period in the Medical Services data (ICD-9-CM 290-319, excluding 299) or Hospital Discharge Abstracts data (ICD-9-CM 290-319, excluding 299; ICD-10-CA F00-F99, excluding F84). The data sources were also searched to determine whether a child met criteria for having a co-morbid intellectual and developmental disability[5] (IDD; see Appendix).

Records in the study dataset were then grouped into one of three diagnostic categories: 1) service provider-reported cases without an administrative diagnosis of ASD; 2) service provider-reported cases with an administrative diagnosis; and 3) administrative diagnosis only.

Verifying diagnostic status for "administrative diagnosis only" group

To verify whether those in the "administrative diagnosis only" group had been clinically diagnosed with ASD, MCHP prepared a

file containing their encrypted PHINs, dates of birth, and sex. This file was sent to MHSAL, where the records were re-identified and the contact information for the children's parents or legal guardians ("parents") was ascertained. MHSAL mailed information letters and consent forms to the parents.

A research assistant telephoned parents who returned a consent form to verify whether any of their children born between 1997 and 2009 had been diagnosed with ASD or another developmental disorder. In the event of an ASD diagnosis, the parents were asked what type of professional made the diagnosis and the date of diagnosis. For those who consented to have their children's information linked to records in the study dataset, the same set of identifiers abstracted from service providers' files was collected. A similar process to the one described earlier was followed to maintain confidentiality and to link the diagnostic information collected from respondents to records in the study dataset.

Analysis

The distribution of ASD codes in the administrative data was examined to specify the algorithms to test among three age groups: 2–5 years, 6–9 years and 10–14 years (as of December 31, 2011). The denominator for calculating sensitivity included all cases within a particular age group who were identified by one or more of the four service providers. The numerator included the subset of those cases with a particular combination of ASD codes in the administrative data on or before December 31, 2011.

Similarly, the denominator for calculating the positive predictive value (PPV) included those individuals in the age group of interest

Table 2. Data sources and codes used to identify children and youth in Manitoba with administrative diagnosis of autism spectrum disorder

Data source	Description	Codes used to identify administrative diagnosis of autism spectrum disorder
Medical Services	Contains physician claims, which are submitted by fee-for-service physicians and by those compensated through alternative payment mechanisms; one "most responsible" diagnosis is recorded to the third digit of the ICD-9-CM.	ICD-9-CM 299 ("Pervasive Developmental Disorders")

Hospital Discharge Abstracts	Contains information on admissions to acute and chronic care facilities, and out-patient surgeries provided in a hospital setting; a maximum of 16 diagnoses are coded to the fifth digit of the ICD-9-CM for encounters up to March 31, 2004 and a maximum of 25 diagnoses are coded to the fifth digit of the ICD-10-CA from April 1, 2004 onwards.	In any of the diagnostic fields:
		ICD-9-CM
		  299.0 ("Autistic disorder")
		  299.8 ("Other specified pervasive developmental disorders")
		  299.9 ("Unspecified pervasive developmental disorder")
		ICD-10-CA
		  F84.0 ("Childhood autism")
		  F84.1 ("Atypical autism")
		  F84.5 ("Asperger syndrome")
		  F84.8 ("Other pervasive developmental disorders")
		  F84.9 ("Pervasive developmental disorder, unspecified")

Education (Special Needs data file)	The Education data contain enrollment and assessment information from the 1995/1996 school year onwards for kindergarten to Grade 12 students, including those who attend private schools or are home-schooled. The Special Needs data file includes a nominal variable (CATEGORYN) that indicates whether a child received funding under a special needs category, one of which is "ASD".	"ASD" [For the algorithms evaluated in this paper that relied on the Education data, we did not use the *STATUSN* variable in the Special Needs data file, which indicates whether Level 2 or Level 3 special needs funding was approved, denied, non-supportable or terminated. This is because 22 of the service provider-reported cases who were only identified in the Education data were never approved for special needs funding support up to December 31, 2011 (data not shown in tabular format).]
Manitoba Adolescent Treatment Centre Database*	The Manitoba Adolescent Treatment Centre provides a range of mental health services to children and adolescents with psychiatric and/or emotional disorders. The Manitoba Centre for Health Policy's Research Data Repository contains Manitoba Adolescent Treatment Centre data from September 1985 onwards.	NDC-A 312 0.92 (indicates enrolment in Autism Treatment Program)

* This is a database housed in the Manitoba Centre for Health Policy's Population Health Research Data Repository. It is distinct from the data abstracted at the Manitoba Adolescent Treatment Centre for this project, as described in the main text under the subheading, *Identification of clinically diagnosed cases of ASD*.

who had a particular combination of ASD codes on or before December 31, 2011. The numerator included the subset of those individuals who were identified by one or more of the four service providers, or who had a parent-reported diagnosis of ASD on or before December 31, 2011. Exact binomial 95% confidence intervals were generated for the observed sensitivity and positive predictive values.[6]

For the sensitivity cohort, we compared various characteristics (e.g., sex, age at diagnosis, presence of a diagnostic code indicating another mental or behavioural disorder) of those who did and did not have an administrative diagnosis of ASD using Pearson's chi-square test.

Study approvals

This study was reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (where the study coordinating centre was located) and the University of Manitoba Health Research Ethics Board. The study was approved by Manitoba's Health Information Privacy Committee and research review/access committees at the service providers where the data abstraction was conducted. Approval was also obtained from Manitoba Education and Training and the Manitoba Adolescent Treatment Centre to access their data housed in the Data Repository.

RESULTS

The number of cases identified by each service provider ranged from 320 to 1279, and 98.5% to 100% of the records containing the child identifiers linked to a valid PHIN. Once the files from the

service providers were merged at MCHP, there were 1728 unique cases overall reported by the service providers.

A total of 2414 children born between 1997 and 2009, inclusive, were identified with an administrative diagnosis of ASD. Once those records were merged and linked with those for the service provider-reported cases, the total number of individuals in the study dataset was 2610 (Figure 1).

Among the children in the "service provider-reported cases with an administrative diagnosis" group ("B" in Figure 1) who had an ICD-9-CM 299 code in the Medical Services data ($n = 1317$), 357 (27.1%) had only one code in that source over the study period, and a further 267 (20.3%) had only two codes recorded in that data source. Among those who had two or more codes ($n = 960$), the median number (interquartile range) recorded over the study period was 4.0 (4.0).

An "ASD" special needs designation can only be recorded once per school year in the Education data. For those service provider-reported cases identified in the Education data ($n = 1091$), a small number only had one ($n = 64$ (5.9%)) or two ($n = 28$ (2.6%)) "ASD" special needs codes in the Education data over the study period, while the remaining 999 (91.6%) had three or more codes recorded.

Records for 882 children made up the "administrative diagnosis only" group ("C" in Figure 1). MHSAL cannot send child-related correspondence to parents once a child is 18 years of age. Ninety-two of those in the "administrative diagnosis only" group were born in 1997 (and hence turned 18 in 2015, when the study packages were mailed to parents). Another 90 children no longer lived in Manitoba. Thus, study packages were mailed to the parents

A: Service provider–reported cases with no administrative diagnosis of autism spectrum disorder

B: Service provider–reported cases with administrative diagnosis of autism spectrum disorder

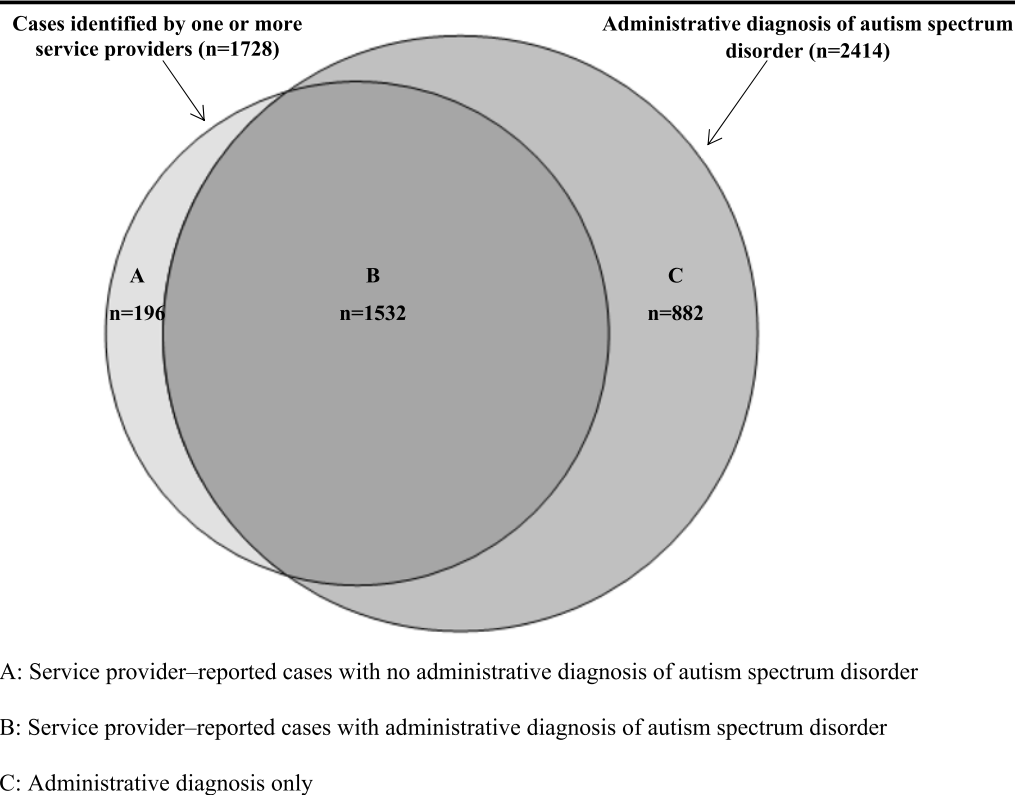C: Administrative diagnosis only

Figure 1. Study dataset prior to verifying diagnostic status for those in "administrative diagnosis only" group ($n = 2610$)

of 700 children in this group. The response rate was very low: only 16 consents were received. Fifteen parents were interviewed (one parent could not be reached, despite numerous attempts) and 13 provided consent to have their children's data linked to records in the study dataset. Once the crosswalk file had been prepared, the diagnostic information provided by parents linked to 14 records in the "administrative diagnosis only" group. Of those, nine had a parent-reported diagnosis of ASD over the study period, and hence were considered true positives. Three had never been diagnosed with ASD, and two had been diagnosed with ASD but only in 2012 or later. These five were therefore known false positives. The diagnostic status could not be confirmed for the remaining 868 in the "administrative diagnosis only" group. As a result, we could only calculate minimum PPVs, whereby those whose diagnostic status could not be confirmed were included in the denominator but not in the numerator (i.e., they were assumed to be false positives for the purpose of calculating a minimum PPV). The estimated sensitivity and minimum PPVs of the algorithms tested are shown in Table 3.

Table 4 compares characteristics of the service provider-reported cases who did and did not have an administrative diagnosis of ASD as of December 31, 2011 ($n = 1532$ and $n = 196$ respectively). Compared to the former group, the latter were more likely to have been born outside Manitoba, to have been diagnosed at a later age, and to have a co-morbid IDD.

DISCUSSION

The primary aim of this work was to recommend an administrative case definition of ASD for surveillance purposes. Our decision-making was based on achieving a balance between a relatively high sensitivity (~80% or higher) and minimum PPV (~70% or higher, recognizing that the true PPV is likely higher than this). Our recommendations are as follows:

- For the 2–5 year age group, ≥1 code in the Medical Services or Education data (algorithm A3 in Table 3).
- For the 6–14 year age group, ≥2 codes in the Medical Services data or ≥1 code in the Education data (algorithms B7 and C7 in Table 3).

Both definitions rely on data from the health and education sectors, even for the youngest age group. Physician claims databases are likely to miss cases, as the extent to which services provided by physicians compensated through non-fee-for-service structures are captured in these databases – through shadow billings – is unknown (or they are not captured).[7] When one also considers that professionals other than physicians can diagnose ASD, special education records are an important supplementary source for maximizing ASD case capture using administrative data.

Even when all four administrative data sources were searched, however, the observed sensitivity was 88%–90% (Table 3, algorithms A5, B9 and C9). Although high, it does mean that 10%–12% of cases were not identified using the administrative data. As shown in Table 4, certain characteristics seem to increase the likelihood of this occurring. These include being born out of province, being diagnosed at a later age and/or by a psychiatrist, and having a co-morbid IDD. While this study was not designed to test the reasons for this (and these factors are likely not

independent of one another, e.g., having a co-morbid IDD may complicate the diagnosis of ASD[8]), it seems reasonable to assume that at least some of the individuals born outside of Manitoba may also have been diagnosed out of province, and thus they may not be captured in the Medical Services data. They may not be identified as a case in the Education data either if they also are on the milder end of the autism spectrum. Being diagnosed at a later age may be related to ASD severity,[9] which again, may affect case capture in the Education data. Finally, those with a co-morbid IDD may be missed because of coding restrictions: records in the Medical Services data were limited to one diagnostic field during the period covered by this analysis,[7] and only one Special Education code can be assigned during a school year. Thus, our data suggest that certain groups may be under-represented in administrative data-based surveillance of ASD in Manitoba, which could have implications in terms of accurately characterizing the ASD population in Manitoba in order to plan services.

The use of administrative data invariably captures false positives, although the extent of the problem is condition-dependent.[10] Some of this may be due to the non-specificity of the diagnostic codes recorded in physician claims databases. In Manitoba, the Medical Services data are only coded to the third digit of the ICD-9-CM and the "299" code captures diagnoses other than ASD (although conditions like childhood disintegrative disorder (ICD-9 299.1) are very rare[11]). In general, the specification of two or more physician claims decreases the number of false positives,[10] which also seems to be the case for ASD.

The potential risk of selection bias due to non-random sampling of sites to derive the validation cohort was minimized by the inclusion of cases from multiple agencies. The identification of cases through specialized diagnostic and assessment centres, like the Child Development Clinic, could artificially inflate the estimated sensitivity of the administrative data.[6] However, our validation cohort also included cases who were identified through two service providers (St.Amant, Children's disABILITY Services). Anyone diagnosed with ASD by a qualified professional can be referred to these agencies, not just those who were diagnosed in a specialty setting.

A major limitation of this study was the very low response rate, which precluded estimations of the actual positive predictive value. We originally decided to evaluate the PPV rather than specificity because even small changes in specificity could have a substantial impact on the PPV,[12] given that ASD is not a common condition. To obtain sufficiently precise estimates of specificity in order to be confident that PPVs were within an acceptable range, we would have had to identify and abstract data on a very large sample of individuals without ASD. Given our low response rate, however, we recommend that future efforts at validating these data evaluate their specificity.

The generalizability of our findings to other regions of Canada is difficult to assess. To our knowledge, there has been only one other study that examined the validity of using Canadian administrative data for identifying children with ASD.[2] The reported sensitivity of one or more physician claims for ASD among those 3–16 years of age in that study was 59.7%; by comparison, our observed values ranged from 73% to 85% for males and females combined (Table 3, algorithms A1, B1 and C1). It may be prudent to assume that our findings are not necessarily generalizable then, given the fact that

Table 3. Estimated sensitivity and minimum positive predictive value of Manitoba's administrative data for identifying children and youth with autism spectrum disorder (ASD)

Algorithm	Medical Services	Education	Hospital Discharge Abstracts	Manitoba Adolescent Treatment Centre database	Number of service provider-reported cases with this configuration of ASD codes up to December 31, 2011 (TP$_{Sens}$)	Total number of service provider-reported cases (TP$_{Sens}$ + FN)	Sensitivity (%) (95% CI) [TP$_{Sens}$/(TP$_{Sens}$ + FN)] × 100	Number of service provider- and parent-reported cases with this configuration of ASD codes up to December 31, 2011 TP$_{PPV}$	Number of individuals in administrative data with this configuration of ASD codes up to December 31, 2011 TP$_{PPV}$ + FP	Minimum positive predictive value (%) (95% CI) [TP$_{PPV}$/(TP$_{PPV}$ + FP)] × 100
2–5 years of age, males and females										
A1	≥1 code				272	321	85 (80–88)	273	376	73 (68–77)
A2	≥2 codes				161	321	50 (45–56)	162	183	89 (83–93)
A3	≥1 code	OR ≥1 code			281	321	88 (83–91)	282	385	73 (69–78)
A4	≥2 codes	OR ≥1 code			182	321	57 (51–62)	183	206	89 (84–93)
A5	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	282	321	88 (84–91)	283	389	73 (68–77)
2–5 years of age, males										
A1	≥1 code				221	260	85 (80–89)	222	303	73 (68–78)
A2	≥2 codes				131	260	50 (44–57)	132	149	89 (82–93)
A3	≥1 code	OR ≥1 code			226	260	87 (83–91)	227	308	74 (68–79)
A4	≥2 codes	OR ≥1 code			147	260	57 (50–63)	148	167	89 (83–93)
A5	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	227	260	87 (83–91)	228	310	74 (68–78)
2–5 years of age, females										
A1	≥1 code				51	61	84 (72–92)	51	73	70 (58–80)
A2	≥2 codes				30	61	49 (36–62)	30	34	88 (73–97)
A3	≥1 code	OR ≥1 code			55	61	90 (80–96)	55	77	71 (60–81)
A4	≥2 codes	OR ≥1 code			35	61	57 (44–70)	35	39	90 (76–97)
A5	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	55	61	90 (80–96)	55	79	70 (58–79)
6–9 years of age, males and females										
B1	≥1 code				458	598	77 (73–80)	458	697	66 (62–69)
B2	≥2 codes				347	598	58 (54–62)	347	418	83 (79–86)
B3		≥1 code			407	598	68 (64–72)	411	471	87 (84–90)
B4		≥2 codes			396	598	66 (62–70)	400	455	88 (85–91)
B5	≥1 code	OR ≥1 code			533	598	89 (86–92)	537	831	65 (61–68)
B6	≥1 code	OR ≥2 codes			525	598	88 (85–90)	529	810	65 (62–69)
B7	≥2 codes	OR ≥1 code			503	598	84 (81–87)	507	647	78 (75–81)
B8	≥2 codes	OR ≥2 codes			486	598	81 (78–84)	490	613	80 (77–83)
B9	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	541	598	90 (88–93)	545	842	65 (61–68)
6–9 years of age, males										
B1	≥1 code				374	488	77 (73–80)	374	557	67 (63–71)
B2	≥2 codes				277	488	57 (52–61)	277	329	84 (80–88)
B3		≥1 code			362	488	74 (70–78)	366	438	84 (80–87)
B4		≥2 codes			338	488	69 (65–73)	342	396	86 (83–90)
B5	≥1 code	OR ≥1 code			434	488	89 (86–92)	438	668	66 (62–69)
B6	≥1 code	OR ≥2 codes			427	488	88 (84–90)	431	649	66 (63–70)
B7	≥2 codes	OR ≥1 code			407	488	83 (80–87)	411	523	79 (75–82)
B8	≥2 codes	OR ≥2 codes			392	488	80 (77–84)	396	492	80 (77–84)
B9	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	439	488	90 (87–92)	443	674	66 (62–69)
6–9 years of age, females										
B1	≥1 code				84	110	76 (67–84)	84	140	60 (51–68)
B2	≥2 codes				70	110	64 (54–73)	70	89	79 (69–87)
B3		≥1 code			86	110	78 (69–85)	86	98	88 (80–94)
B4		≥2 codes			80	110	73 (63–81)	80	91	88 (79–94)
B5	≥1 code	OR ≥1 code			99	110	90 (83–95)	99	163	61 (53–68)
B6	≥1 code	OR ≥2 codes			98	110	89 (82–94)	98	161	61 (53–68)
B7	≥2 codes	OR ≥1 code			96	110	87 (80–93)	96	124	77 (69–84)
B8	≥2 codes	OR ≥2 codes			94	110	85 (77–91)	94	121	78 (69–85)
B9	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	102	110	93 (86–97)	102	168	61 (53–68)

Continued

Table 3. (Continued)

Algorithm	Medical Services	Education	Hospital Discharge Abstracts	Manitoba Adolescent Treatment Centre database	Number of service provider-reported cases with this configuration of ASD codes up to December 31, 2011	Total number of service provider-reported cases	Sensitivity (%) (95% CI)	Number of service provider- and parent-reported cases with this configuration of ASD codes up to December 31, 2011	Number of individuals in administrative data with this configuration of ASD codes up to December 31, 2011	Minimum positive predictive value (%) (95% CI)
					(TP$_{Sens}$)	(TP$_{Sens}$ + FN)	[TP$_{Sens}$/(TP$_{Sens}$ + FN)] $\times$ 100	TP$_{PPV}$	TP$_{PPV}$ + FP	[TP$_{PPV}$/(TP$_{PPV}$ + FP)] $\times$ 100
10–14 years of age, males and females										
C1	≥1 code				587	809	73 (69–76)	591	929	64 (60–67)
C2	≥2 codes				452	809	56 (52–59)	455	581	78 (75–82)
C3		≥1 code			589	809	73 (70–76)	589	787	75 (72–78)
C4		≥2 codes			560	809	69 (66–72)	560	722	78 (74–81)
C5	≥1 code	OR ≥1 code			696	809	86 (83–88)	700	1155	61 (58–63)
C6	≥1 code	OR ≥2 codes			682	809	84 (82–87)	686	1114	62 (59–64)
C7	≥2 codes	OR ≥1 code			649	809	80 (77–83)	652	927	70 (67–73)
C8	≥2 codes	OR ≥2 codes			629	809	78 (75–81)	632	876	72 (69–75)
C9	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	709	809	88 (85–90)	713	1183	60 (57–63)
10–14 years of age, males										
C1	≥1 code				481	672	72 (68–75)	483	736	66 (62–69)
C2	≥2 codes				362	672	54 (50–58)	364	462	79 (75–82)
C3		≥1 code			491	672	73 (70–76)	491	661	74 (71–78)
C4		≥2 codes			467	672	69 (66–73)	467	605	77 (74–80)
C5	≥1 code	OR ≥1 code			576	672	86 (83–88)	578	933	62 (59–65)
C6	≥1 code	OR ≥2 codes			564	672	84 (81–87)	566	897	63 (60–66)
C7	≥2 codes	OR ≥1 code			534	672	79 (76–82)	536	766	70 (67–73)
C8	≥2 codes	OR ≥2 codes			517	672	77 (74–80)	519	721	72 (69–75)
C9	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	587	672	87 (85–90)	589	957	62 (58–65)
10–14 years of age, females										
C1	≥1 code				106	137	77 (69–91)	108	193	56 (49–63)
C2	≥2 codes				90	137	66 (57–74)	91	119	76 (68–84)
C3		≥1 code			98	137	72 (63–79)	98	126	78 (70–85)
C4		≥2 codes			93	137	68 (59–76)	93	117	79 (71–86)
C5	≥1 code	OR ≥1 code			120	137	88 (81–93)	122	222	55 (48–62)
C6	≥1 code	OR ≥2 codes			118	137	86 (79–91)	120	217	55 (48–62)
C7	≥2 codes	OR ≥1 code			115	137	84 (77–90)	116	161	72 (64–79)
C8	≥2 codes	OR ≥2 codes			112	137	82 (74–88)	113	155	73 (65–80)
C9	≥1 code	OR ≥1 code	OR ≥1 code	OR ≥1 code	122	137	89 (83–94)	124	226	55 (48–61)

Note: CI = confidence interval; FN = false negatives; FP = false positives (includes known false positives, and those for whom case status could not be ascertained and who were assumed to be false positives for the purpose of calculating a minimum positive predictive value); PPV = positive predictive value; Sens = sensitivity; TP = true positives.

Table 4. Characteristics of service provider-reported cases stratified by absence/presence of administrative diagnosis of autism spectrum disorder (ASD) on or before December 31, 2011

	Administrative diagnosis of ASD		p-value*
	No (*n* = 196)	**Yes** (*n* = 1532)	
Male, %	85.2	81.8	0.24
Age group[†], %			
2–5 years	19.9	18.4	0.22
6–9 years	29.1	35.3	
10–14 years	51.0	46.3	
Born in Manitoba, %	76.0	84.7	0.002
Region of residence, %			
Winnipeg	64.8	65.0	0.75
Southern	14.8	11.9	
Prairie Mountain	10.7	11.2	
Interlake-Eastern	6.6	8.1	
Northern	3.1	3.8	
Age at initial diagnosis of ASD[‡], % (% when "Unknown" excluded)			
<3 years	7.1 (11.8)	20.0 (26.1)	<0.0001
3–5 years	19.9 (32.8)	43.9 (57.3)	
6–9 years	20.4 (33.6)	10.1 (13.1)	
10–14 years	13.3 (21.8)	2.6 (3.4)	
Unknown	39.3	23.5	
Type of professional who made the diagnosis of ASD[‡], % (% when "Unknown" excluded)			
Pediatrician	22.4 (34.9)	62.1 (76.2)	—‖
Psychiatrist	35.2 (54.8)	14.8 (18.2)	
Physician (type unspecified)	6.6 (10.3)	3.5 (4.3)	
Psychologist	—§	1.0 (1.3)	
Unknown	35.7	18.5	
At least one code in administrative data over study period indicating another mental or behavioural disorder, %			
ICD-9-CM 290-319¶ (excluding 299) or ICD-10-CA F00-F99** (excluding F84)	79.1	75.9	0.32
Meets criteria for co-morbid intellectual and developmental disability (see Appendix)	18.9	3.9	<0.0001

* Pearson chi-square test.
[†] As of December 31, 2011.
[‡] Based on data provided by service providers.
§ Suppressed for confidentiality. The percent value has been aggregated with the "Unknown" category.
‖ Could not be calculated due to suppressed value (see table footnote §).
¶ "Mental disorders".
** "Mental and behavioural disorders".

our recommended surveillance case definitions rely on Medical Services data (physician claims) and there are documented differences among physician claims databases across Canada.[7] Moreover, variations in diagnostic practices and special education services for ASD, as well as different funding models for health care, may affect how accurately and completely individuals with ASD can be identified in other regions' administrative health and education data.

Despite these limitations, this work offers the first comprehensive assessment of Manitoba's administrative data for the purpose of conducting ASD surveillance in that province. Although we could only estimate minimum PPVs, the numbers provided will allow the Public Health Agency of Canada to present a range of plausible values for the prevalence of ASD in that province, and will help to advance the goal of establishing a cost-effective national surveillance system for ASD by informing similar work in other regions of the country.

APPENDIX

Criteria to define the presence of a co-morbid (with autism spectrum disorder) intellectual and developmental disability using Manitoba's administrative health and education data

1. Education
   In the Education Special Needs data file, children who received funding for special needs were identified using the variable *CATEGORYN*. A designation of "Multiple Handicaps" ("MH") was used to define a co-morbid intellectual and developmental disability (IDD) if the *STATUSN* variable, which identifies whether funding was approved, denied, non-supportable or terminated, indicated that funding was approved.

2. Medical Services Database
   The following ICD-9-CM codes were used to define a co-morbid IDD:
   - 317 ("Mild mental retardation")
   - 318 ("Other specified mental retardation")
   - 319 ("Unspecified mental retardation")

3. Hospital Discharge Abstracts
   The following ICD-9-CM and ICD-10-CA codes in any of the diagnosis fields (see Table 2) were used to define a co-morbid IDD:
   ICD-9-CM
   - 317 ("Mild mental retardation")
   - 318 ("Other specified mental retardation")
   - 319 ("Unspecified mental retardation")
   - 758.0-758.3 ("Chromosomal anomalies")
   - 759.81-759.89 ("Other and unspecified congenital anomalies")
   - 760.71 ("Fetal alcohol syndrome")
   ICD-10-CA
   - F70.0, F70.1, F70.8, F70.9 ("Mild mental retardation")
   - F71.0, F71.1, F71.8, F71.9 ("Moderate mental retardation")
   - F72.0, F72.1, F72.8, F72.9 ("Severe mental retardation")
   - F73.0, F73.1, F73.8, F73.9 ("Profound mental retardation")
   - F78.0, F78.1, F78.8, F78.9 ("Other mental retardation")
   - F79.0, F79.1, F79.8, F79.9 ("Unspecified mental retardation")
   - P04.3 ("Fetus and newborn affected by maternal use of alcohol")
   - Q86.0, Q86.1, Q86.2, Q86.8 ("Congenital malformation syndromes due to known exogenous causes, not elsewhere classified")
   - Q87.0, Q87.1, Q87.2, Q87.3, Q87.5, Q87.8 ("Other specified congenital malformation syndromes affecting multiple systems")
   - Q89.8 ("Other specified congenital malformations")
   - Q90.0, Q90.1, Q90.2, Q90.9 ("Down syndrome")

- Q91.0, Q91.1, 91.2, Q91.3, 91.4, Q91.5, 91.6, Q91.7 ("Edwards syndrome and Patau syndrome")
- Q93.0, Q93.1, Q93.2, Q93.3, Q93.4, Q93.5, Q93.6, Q93.7, Q93.8, Q93.9 ("Monosomies and deletions from the autosomes, not elsewhere classified")
- Q99.2 ("Fragile X chromosome")

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RÉSUMÉ

OBJECTIFS : Évaluer la sensibilité et la valeur prédictive positive (VPP) des données administratives dans le domaine de la santé et de l'éducation pour déceler les cas de troubles du spectre autistique (TSA) au Manitoba et recommander une définition de cas sous surveillance.

MÉTHODE : Quatre dispensateurs de services ont résumé les renseignements d'enfants ayant reçu un diagnostic clinique de TSA (« cohorte de sensibilité »). Ces renseignements ont été maillés avec les données administratives du Manitoba dans le domaine de la santé et de l'éducation, et les dossiers ont été extraits vers le jeu de données de l'étude. Ont aussi été inclus les dossiers des enfants ayant un diagnostic administratif de TSA, mais ne faisant pas partie de la cohorte de sensibilité. La trousse de l'information de l'étude a été envoyée par la poste aux parents de ce dernier groupe pour confirmer le diagnostic des enfants. La sensibilité et la VPP de diverses définitions de cas ont été calculées.

RÉSULTATS : Sur les 1 728 cas déclarés par les dispensateurs de services, 1 532 avaient un diagnostic administratif de TSA. Au total, 2 414 enfants avaient un diagnostic administratif, dont 882 ne faisant pas partie de la cohorte de sensibilité. La réponse à l'envoi postal a été nettement insuffisante (<3 %). Par conséquent, nous avons calculé des VPP minimales. Nos définitions de cas sous surveillance recommandées sont ≥1 demande(s) de paiement de médecin(s) (CIM-9-MC 299) ou ≥1 dossier(s) d'éducation spécialisée « TSA » (2–5 ans), et ≥2 demandes de paiement de médecins ou ≥1 dossier(s) d'éducation spécialisée « TSA » (6–14 ans). La sensibilité variait de 80 % (IC de 95 % : 77–83) à 88 % (IC de 95 % : 83–91) et la VPP minimale de 70 % (IC de 95 % : 67–73) à 78 % (IC de 95 % : 75–81) pour ces définitions.

CONCLUSION : Ce travail nous rapproche de l'objectif d'établir un système de surveillance national économiquement efficace pour les TSA.

MOTS CLÉS : trouble du spectre autistique; surveillance; données administratives; études de validation; Manitoba; Centre d'élaboration et d'évaluation de la politique des soins de santé du Manitoba