ENHANCING SURVEILLANCE OF AUTISM SPECTRUM DISORDERS IN CANADA

Report submitted to the Public Health Agency of Canada
Enhanced Surveillance for Chronic Disease Program
of the Healthy Living and Chronic Disease Strategy

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Please be advised that this report is best viewed on the screen or printed in colour.

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Acknowledgements

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Steering Committee

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The Manitoba Centre for Health Policy

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Executive Summary

Accurate information about the prevalence and incidence of autism spectrum disorders (ASD) in Canada is critical, given the increase in the number of children diagnosed with ASD and the high lifetime cost associated with these disorders, which is estimated at about $2 million per person (Autism Society Canada, 2004). Having a national strategy to monitor and provide surveillance of ASD is crucial to a better understanding of the observed increase in the number of reported cases of ASD. In 2006, the Canadian Minister of Health announced the intention of the Federal Government to enhance monitoring, research, knowledge-sharing, and best practices in the field of ASD.

Enhancing Surveillance of Autism Spectrum Disorders in Canada presents an exploration of how administrative datasets can be used to improve the surveillance of autism spectrum disorders (ASD) in Canada. It addresses three questions:

1. How to best identify children diagnosed with an ASD in administrative databases?

2. Which surveillance indicators can be collected in administrative databases?

3. What are the potential catchment areas where ASD surveillance can be expanded?

Main messages

Identification of children diagnosed with an ASD in administrative databases raises several data quality issues. We recommend the development and validation of an algorithm to capture ASD cases in administrative databases.

Many surveillance indicators can be collected in administrative databases, but none of the studied databases contains information on all the relevant indicators. Using multiple data sources increases the breadth of our understanding of ASD, although it complicates data collection. We recommend a re-examination of which indicators should (and can) be collected as part of an ASD surveillance program using administrative databases.

Manitoba, Ontario, Quebec, Alberta and British Columbia have infrastructures to facilitate data collection and linkage for ASD surveillance using administrative databases. However, significant work is needed to develop the required partnerships and data sharing agreements. Data sources, data collection and access procedures, as well as established partnerships and data sharing agreements vary greatly across provinces.

Background

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC, www.nedsac.ca) has been investigating the epidemiology of ASD in Canada since its formation in 2001. Currently, researchers, clinicians and government agencies from four regions of Canada contribute data to NEDSAC: Manitoba, South Eastern Ontario, Newfoundland and Labrador and Prince Edward Island. In 2007, the Public Health Agency of Canada put out a request for proposals to evaluate tools and

methods to enhance chronic disease surveillance in Canada. Under that request, we proposed two broad objectives. The first was to use administrative data to evaluate our existing ASD surveillance efforts, by examining the completeness of our case capture and exploring additional indicators that can be captured in administrative datasets. The second was to identify additional catchment areas to expand surveillance activities to other regions of Canada.

Manitoba was chosen as the pilot site for the first objective. Under the current NEDSAC protocol, children with ASD are identified through Children's Special Services, a provincial program that serves children with special needs throughout the province (excluding those living on reserves). Manitoba offers an exceptional opportunity to access and link multiple administrative databases. The Manitoba Centre for Health Policy (MCHP, www.mchp.ca) houses population-based anonymized databases on the use of physicians, hospitals, home care, nursing homes and prescription drugs. It also has anonymized information from other sectors, including education and social services. The second reason we decided to undertake this work in Manitoba was the low prevalence of ASD estimated through NEDSAC for that province. The most recent prevalence figures reported by NEDSAC were for 2006 (National Epidemiologic Database for the Study of Autism in Canada, 2008). At that time, the estimated prevalence of ASD among children 2–14 years of age in Manitoba was 44.6 per 10,000, or 1 in 224. Although the prevalence was not broken down for individual ages in that report, among 8–year–olds the prevalence was 66.0 per 10,000, or 1 in 152. By comparison, the Centers for Disease Control and Prevention reported a prevalence of 1 in 110 for children 8 years of age in 2006 (Centers for Disease Control and Prevention, 2009). Thus, we suspected we were underestimating the true prevalence of ASD in Manitoba. The findings from Manitoba will also inform the feasibility of expanding surveillance activities to other regions of Canada using similar administrative databases.

Key findings and next steps

The key findings are as follows:

1. The prevalence of ASD in Manitoba estimated using data from NEDSAC is substantially lower than the prevalence estimated using data from the MCHP.
2. A potential data quality issue was identified in relation to updating the status of individuals in NEDSAC under the current protocol.
3. Several potential data quality issues were identified in terms of including individuals in prevalence estimates for the correct study years under NEDSAC's current protocol.
4. Without further investigation, we cannot determine whether the 299 ICD-9 code has sufficient specificity to allow us to consider evaluating the completeness of NEDSAC's case capture. It is particularly relevant to Ontario where NEDSAC considered using administrative health data from the Institute for Clinical Evaluative Sciences (ICES).
5. Using the MCHP data would expand the list of reportable indicators considerably compared to using NEDSAC alone.
6. There are several potential and known data quality issues related to capturing certain indicators in the MCHP data.

7. There are some indicators currently collected in NEDSAC that are not available in the MCHP data.
8. Ontario, Québec, Alberta and British Columbia have infrastructures to facilitate data linkage for ASD surveillance using administrative data; however, significant work will be required to develop the required partnerships and data sharing agreements.
9. In Prince Edward Island and Newfoundland and Labrador, there is no need to alter NEDSAC's current data collection (reliance on service provision data) to administrative data linkage.

Recommended next steps are as follow:

1. Develop and validate an algorithm to define ASD case status in Manitoba using administrative data. This will require testing different combinations of ASD coding in the administrative data at MCHP (e.g. one claim in Physician Billing data only, at least one claim in Physician Billing data, at least one claim in Physician Billing data AND at least one claim in Education data, etc.) against a gold standard chart review to determine how best to assign case status using administrative data in Manitoba.
2. Determine whether the date an ASD code first appears in Health, and, if possible, Education data at MCHP accurately reflects the date of diagnosis.
3. Re-evaluate which indicators should be collected as part of an ASD surveillance program using administrative data.
4. Develop a protocol for access to indicators that can be accurately captured in the MCHP datasets and are not captured in NEDSAC.
5. Work with MCHP and Child and Family Services to add inFACT data (including ASD diagnostic information) to the annual data transfer from Family Services and Consumer Affairs to MCHP.
6. Continue to collect information in Manitoba using the current NEDSAC protocol until the above agreement is reached (recommendation #5).
7. Engage in discussions with identified data holders in Ontario, Québec, Alberta and British Columbia to develop partnerships for ASD surveillance using administrative data guided by current and future findings in Manitoba (re: recommendations #1, 2 and 3).
8. Continue to collect information in South Eastern Ontario using the current NEDSAC protocol until the above agreement is reached (recommendation #7).
9. Continue to collect information in Prince Edward Island and Newfoundland and Labrador using the current NEDSAC protocols.
10. Work with the Public Health Agency of Canada to complete a capacity review for ASD surveillance using administrative data in the remaining three provinces and three territories.
11. Secure funding to undertake the recommended actions.

List of Abbreviations

ADI	Autism Diagnostic Interview
ADOS	Autism Diagnostic Observation Schedule
AHCIP	Alberta Health Care Insurance Plan
ASD	Autism Spectrum Disorders
ASD-CARC	Autism Spectrum Disorders–Canadian-American Research Consortium
BCAAN	British Columbia Autism Assessment Network
CD	Census division
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes of Health Research
CMA	Census Metropolitan Area
CRDITED	Centre de réadaptation en déficience intellectuelle et troubles envahissants du développement
CSD	Census subdivision
CT	Census tract
DA	Dissemination area
DAD	Discharge Abstract Database
DPL	Designated place
DSM	Diagnostic and Statistical Manual
FRSQ	Fonds de recherche en santé du Québec
FSA	Forward sortation area
ICD	International Classification of Diseases
ICES	Institute of Clinical Evaluative Sciences
MCHP	Manitoba Centre for Health Policy
MELS	Ministère de l'Éducation, des Loisirs et du Sport
MESS	Ministère de l'Emploi et de la Solidarité sociale
MIMS	Manitoba Immunization Monitoring System
MOMBABY	Mother-Baby Linked Database
MSSS	Ministère de la Santé et des Services sociaux
NACRS	National Ambulatory Care Reporting System
NEDSAC	National Epidemiologic Database for the Study of Autism in Canada
OHIP	Ontario Health Insurance Plan
PHAC	Public Health Agency of Canada

PHIN	Personal Health Identification Number
PIA	Privacy Impact Assessment
RAMQ	Régie de l'assurance maladie du Québec
RPDB	Registered Persons Database
RRQ	Régie des rentes du Québec
SAMIN	Social Assistance Management Information Network
SICDI	Système d'information clientèle : Déficience intellectuelle
SIPAD	Système d'information des personnes ayant une déficience
TRA	Threat Risk Assessment
UA	Urban area

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Introduction

Autism Society Canada (2004) estimates that the number of reported cases of autism spectrum disorders (ASD) grew by more than 150 percent over a six-year period. Current estimates place the number of cases at about 1 in 110 children (Centers for Disease Control and Prevention, 2009). Accurate information about the prevalence and incidence of ASD in Canada is critical, given the high lifetime cost associated with these disorders, which is estimated at about $2 million per person (Autism Society Canada, 2004). Having a national strategy to monitor and provide surveillance of ASD is crucial to a better understanding of the observed increase in the number of reported cases of ASD. Surveillance systems aim to "track and forecast any health event or health determinant through the ongoing collection of data, the integration, analysis and interpretation of that data into surveillance products and the dissemination of that resultant surveillance product to those who need to know" (Health Canada, 1999).

In 2006, the Canadian Minister of Health announced the intention of the Federal Government to enhance monitoring, research, knowledge-sharing, and best practices in the field of ASD. The Public Health Agency of Canada (PHAC) took a leadership role and undertook a series of activities meant to facilitate the development of surveillance of ASD in Canada. In 2007, within the Enhanced Surveillance for Chronic Diseases Program, PHAC announced a request for proposals (not specifically targeting ASD) to evaluate tools and methods to enhance chronic disease surveillance in Canada.

In response to that request, the investigators of the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC; www.nedsac.ca), led by Hélène Ouellette-Kuntz, proposed to address two broad objectives. The first was to use administrative data to evaluate NEDSAC's existing ASD surveillance efforts in one region, by examining the completeness of its case capture and exploring additional indicators that can be captured in administrative datasets. The second was to identify additional catchment areas to expand surveillance activities to other regions of Canada. That proposal was successful and funding from the Public Health Agency of Canada was received in 2009.

Purpose of this report

This report describes activities undertaken by NEDSAC from 2009 to 2011 to meet the proposed objectives and presents recommendations to enhance surveillance of ASD in Canada. As such, the purpose of this report is to explore how administrative datasets can be used to improve NEDSAC's existing system for ASD surveillance in Canada.

In Part 1, we present activities undertaken in Manitoba to evaluate case ascertainment methods and identify additional surveillance indicators that can be collected by linking data held by the Manitoba Centre for Health Policy**.**

In Part 2 we explore potential additional catchment areas that would allow us to feasibly expand surveillance activities to other regions of Canada.

Part 3 consists of a summary of key findings and a list of recommended next steps to establish a national ASD surveillance program using administrative data.

PART 1. Improving NEDSAC using administrative datasets: Exploration in Manitoba

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC, www.nedsac.ca) has been investigating the epidemiology of ASD in Canada since its formation in 2001. NEDSAC received funding from the Canadian Institutes of Health Research from 2001 to 2011 (Team grant from 2001 to 2006 and Programmatic operating grant from 2006 to 2011).

To our knowledge, NEDSAC is the only Canadian initiative that is collecting multi-site and ongoing data on children with ASD. One of the main goals of NEDSAC is to monitor the prevalence of ASD among Canadian children, in order to 1) provide data for policy makers and planners who serve this population; 2) determine whether there are geographic or temporal trends in the prevalence of ASD, age at diagnosis, sex ratio, ethnicity and other factors; and 3) formulate hypotheses regarding potential etiologic factors. As part of NEDSAC collaboration, researchers, clinicians and government agencies from four regions of Canada contribute data to NEDSAC: Manitoba, South Eastern Ontario, Newfoundland & Labrador and Prince Edward Island.

The data made available to NEDSAC comprises basic demographic and diagnostic information, including the child's date of birth and sex, number of siblings, number of siblings with an ASD, ethnicity, parental ages when the child was born, place where the mother was living when pregnant with the affected child, and, for the current and initial ASD diagnoses, information on who made the diagnosis, the tests that were used, the date of diagnosis and the diagnostic subtype. Data collection approaches vary from one region to another (see Ouellette-Kuntz et al., forthcoming).

Children's Special Services, a program of the Manitoba Department of Family Services and Consumer Affairs that provides services to all special-needs children in the province, identifies cases of ASD to NEDSAC. Children's Special Services has seven regional offices throughout Manitoba. Staff at each office complete NEDSAC data collection forms on an ongoing basis for newly identified cases, and submit update forms when a previously identified case has moved, died, left the agency for some other reason, or has the diagnosis of ASD removed.

Although Manitoba is only one of four current NEDSAC surveillance sites, it was chosen as the focus of this study for two reasons. First, a well-developed administrative data infrastructure exists in Manitoba, which allowed us to compare cases of ASD captured in NEDSAC with those identified in physician billing claims, hospital discharge abstracts and Education data. The Manitoba Centre for Health Policy (MCHP) offers an exceptional opportunity to link multiple administrative databases. The MCHP houses comprehensive anonymized databases on the use of physicians, hospitals, home care, nursing homes and prescriptions by the Manitoba population. It also has anonymized information on education and family services. Linking the data in NEDSAC with the MCHP's Health and Education data allows us to compare the prevalence estimates obtained using the MCHP data with those derived

through NEDSAC. The second reason we decided to undertake this work in Manitoba was the low prevalence estimated through NEDSAC for that province. The most recent prevalence figures reported by NEDSAC were for 2006 (National Epidemiologic Database for the Study of Autism in Canada, 2008). At that time, the estimated prevalence of ASD among children 2–14 years of age in Manitoba was 44.6 per 10,000, or 1 in 224. Although the prevalence was not broken down for individual ages in that report, among 8–year–olds the prevalence was 66.0 per 10,000, or 1 in 152. By comparison, the Centers for Disease Control and Prevention reported a prevalence of 1 in 110 for children 8 years of age in 2006 (Centers for Disease Control and Prevention, 2009). Thus, we suspected we were underestimating the true prevalence of ASD in Manitoba[a].

In 2009, NEDSAC received funding from the Public Health Agency of Canada to (1) evaluate case ascertainment methods in Manitoba, and (2) identify additional surveillance indicators that can be collected by linking data held by the Manitoba Centre for Health Policy. The findings from Manitoba will also inform the feasibility of expanding surveillance activities to other regions of Canada.

Chapter 1 presents preliminary activities which were required to access and link datasets. Chapter 2 reports findings and recommendations regarding case ascertainment methods in Manitoba. Chapter 3 discusses additional surveillance indicators that can be collected by linking data held by the MCHP.

[a] It is important to note, however, that the Centers for Disease Control reviews health and education records and assigns case status based on whether the child meets DSM-IV criteria for autism spectrum disorder, regardless of whether a formal diagnosis has been made (Centers for Disease Control and Prevention, 2009).

Chapter 1: Accessing and linking datasets at the Manitoba Centre for Health Policy

The Manitoba Centre for Health Policy (MCHP) provides an exceptional opportunity to access and link multiple administrative datasets. Appendix 1 presents a detailed description of the datasets held by the MCHP that are relevant to ASD surveillance.

The Manitoba Centre for Health Policy

The Manitoba Centre for Health Policy (MCHP, www.mchp.ca) is a research unit in the University of Manitoba's Faculty of Medicine that conducts population-based research on health services, population and public health, and the social determinants of health. The MCHP develops and maintains a comprehensive, population-based data repository on behalf of the Province of Manitoba. The Population Health Research Data Repository is a comprehensive collection of administrative, registry, survey and other databases that primarily covers residents of Manitoba. The MCHP Repository consists of databases received from Manitoba Health and Healthy Living, Manitoba grade and high schools and post-secondary colleges, Healthy Child Manitoba and Community and Social Services.

All the datasets available in the MCHP Repository were examined to identify sources of data relevant to the surveillance of ASD. A detailed presentation of relevant data sources has been provided in Appendix 1. After consultation with scientists and analysts at MCHP, the databases of greatest interest to ASD surveillance were identified, and the ability to link them was determined. Of interest to the work in ASD surveillance, were the Hospital Discharge Abstracts and the Medical Claims, as well as non- health administrative data such as Education and Social Services. The review process took 3 to 4 months to complete before a proposal and work plan could be developed.

Approvals for accessing data

Permission to use the data had to be secured and obtained before any work could be started. The initial step was to prepare data sharing agreements between the University of Manitoba and Queens' University. Once, these were obtained, the next step was the MCHP Feasibility Assessment which involved research team members from both the University of Manitoba and Queens' University. The MCHP determined the validity of the project and scrutinized how their data would be used and if the objectives could be met. This MCHP feasibility approval formed the basis of the next approvals that were required with Manitoba Health, as well as with Manitoba Family Services and Consumer Affairs and Manitoba Education.

The study protocol was also sent to the Research Ethics Boards of the University of Manitoba and Queen's University for approval. These were renewed yearly based on the duration of the research project. An application was also made to the Manitoba Health Information Privacy Committee, which ensured privacy and confidentiality legislation and protection of health information were upheld.

A signed agreement with the Government of Manitoba and the University of

Manitoba to allow the use of the MCHP data was the final document required to complete the approval process.

We started the approval process in the third month of funding and all approvals and agreements were concluded in the twelfth month. The nine-month process of completing all these agreements and approvals provides important information for future work using administrative databases. When planning research projects, the first year of funding is likely to be dedicated to becoming familiar with the content and limitations of the various administrative databases and to obtaining required approvals to access the required data elements.

Preparation of study dataset

To meet the study's objectives, the dataset must include all children with an ASD identified through either NEDSAC or any one of the identified databases held at the MCHP. For case estimates to be accurate, duplicates must first be identified and removed from the count. Therefore, to prepare the study dataset, we must be able to link all data sources using a unique identifier for each case.

Decoding the identities of NEDSAC cases

The first step in preparing the study dataset was to provide a list of identifiers (first two letters of the child's surname and first name, date of birth and sex) for prevalent cases of ASD in NEDSAC for 2002–2007 (n=1146) to Children's Special Services, which originally provided this information. Included with these identifiers were six columns to indicate whether a child was considered a prevalent case of ASD in NEDSAC for each year from 2002–2007, inclusive. The seven Children's Special Services regional offices throughout Manitoba used the identifiers provided to decode the identity of individuals and attach names and inFACT ID numbers (a unique identifier used by Children's Special Services) to the records. Identities could not be decoded for 52 records[b], and therefore no inFACT ID numbers were attached to these records. A duplicate inFACT ID number was assigned to eight pairs of records, five of which were later determined to be duplicate cases. The files were then forwarded to the central Children's Special Services office in Winnipeg, which scrambled the inFACT ID numbers and copied the files. One set of copied files, containing only the scrambled inFACT ID numbers and the six columns to indicate whether the child was a prevalent case in NEDSAC for 2002–2007, was forwarded to the MCHP. The other set of copied files, containing names, scrambled inFACT ID numbers, dates of birth and sex, were forwarded to Manitoba Health.

Preparation of Crosswalk File at Manitoba Health

Manitoba Health used the names, dates of birth and sex to attach encrypted Personal Health Identification Numbers (PHINs) to the NEDSAC records, and

[b] Children's Special Services reported that they could not decode the identity of 46 individuals, and therefore could not attach an inFACT ID number to those records. Manitoba Health reported that scrambled inFACT ID numbers were missing for 52 records. This discrepancy in numbers was not resolved.

removed other identifying information. No PHIN could be found for 271 records[c], which meant that 818 of 1089 records (75.1%, taking into account that of the 1146 NEDSAC records 52 identities could not be decoded and there were 5 duplicate records) linked to a valid PHIN. The crosswalk file that contained scrambled inFACT ID numbers and encrypted PHINs was sent by Manitoba Health to the Manitoba Centre for Health Policy. A schematic of the preliminary steps described above is shown in Figure 1.1.

Merging files at the Manitoba Centre for Health Policy (MCHP)

Files at the Manitoba Centre for Health Policy (MCHP) are merged based on encrypted PHINs. The crosswalk file prepared by Manitoba Health allowed records in NEDSAC to be linked to records in the MCHP datasets described in Appendix 1. A prevalent case of ASD for any of the study years from 2002–2007 was considered to be a child under the age of 15 years[d] who lived in Manitoba at any point during the study year and who met one or more of the following criteria. Note that children living on First Nations reserves were excluded from the study dataset, as they are not included in NEDSAC.

a) The Hospital Abstracts Database: a code of 299.0, 299.1, 299.8, 299.9, F84.0, F84.1, F84.2, F84.3, F84.4, F84.5, F84.8 or F84.9 at any time from 1988 up to and including the study year.

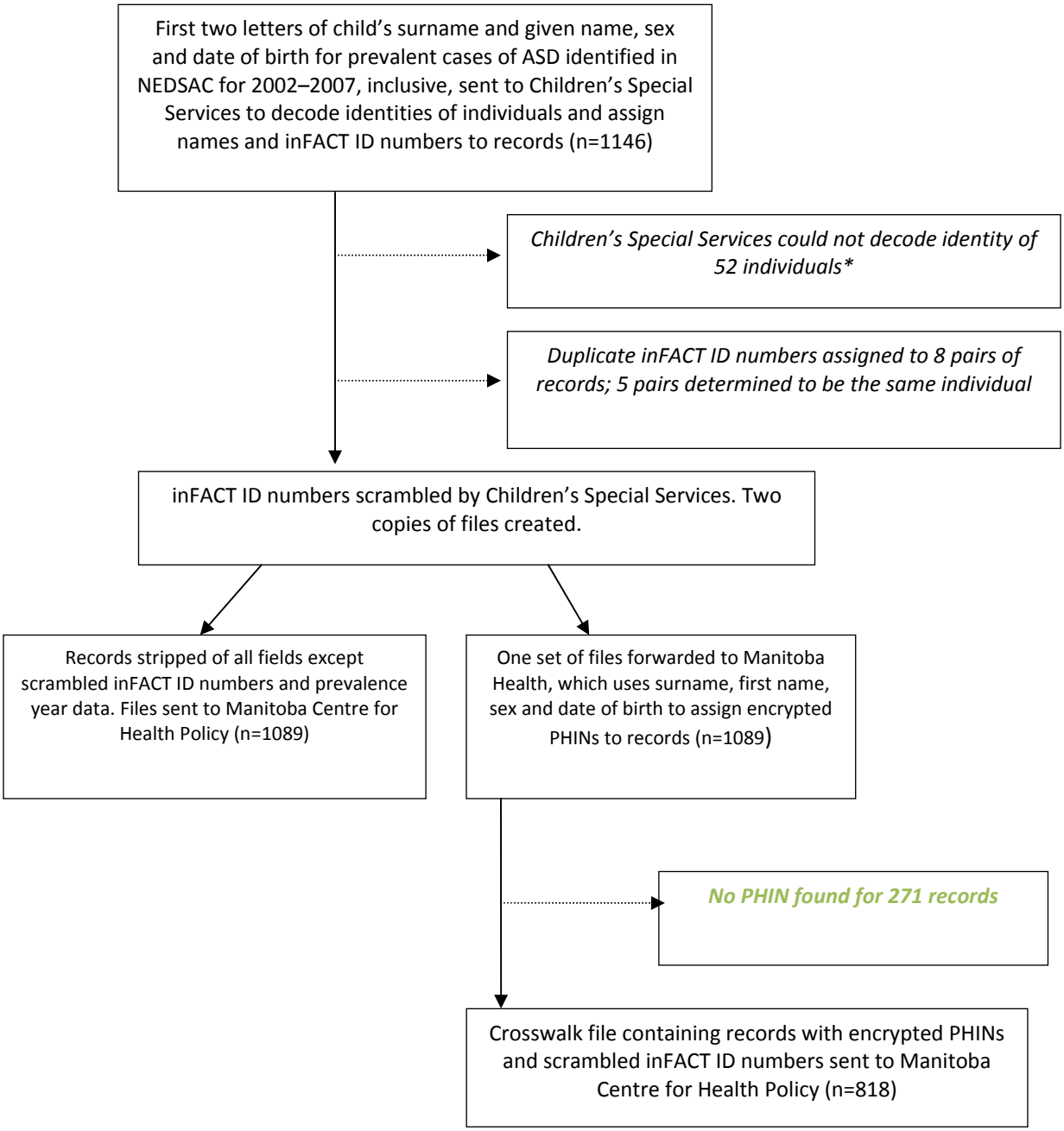
b) The Medical Services Database: a code of 299 at any time from 1988 up to and including the study year.

c) The Education Database: a special needs category of "ASD" at any time from 1995 (first year of data availability) up to and including the study year.

d) NEDSAC: a record in the dataset coded with a "1" for that study year.

[c] The analyst at the MCHP reported similar distributions for birth year, sex and reporting Children's Special Services regional office for the 818 records where a valid PHIN could be assigned and the 271 records where one could not.
[d] As of December 31 of the study year

Figure 1.1: Decoding the identity of cases in NEDSAC at Children's Special Services and preparation of crosswalk file at Manitoba Health



*Children's Special Services reported that they could not assign an inFACT ID number for 46 individuals, while Manitoba Health reported that the scrambled inFACT ID number was missing for 52 records. This discrepancy was not resolved, but scrambled inFACT ID numbers and encrypted PHINs were missing for 52 records in the crosswalk files forwarded by Manitoba Health to the Manitoba Centre for Health Policy.

Figure 1.2: Cases of autism spectrum disorders identified in each of the data sources (n=2679)

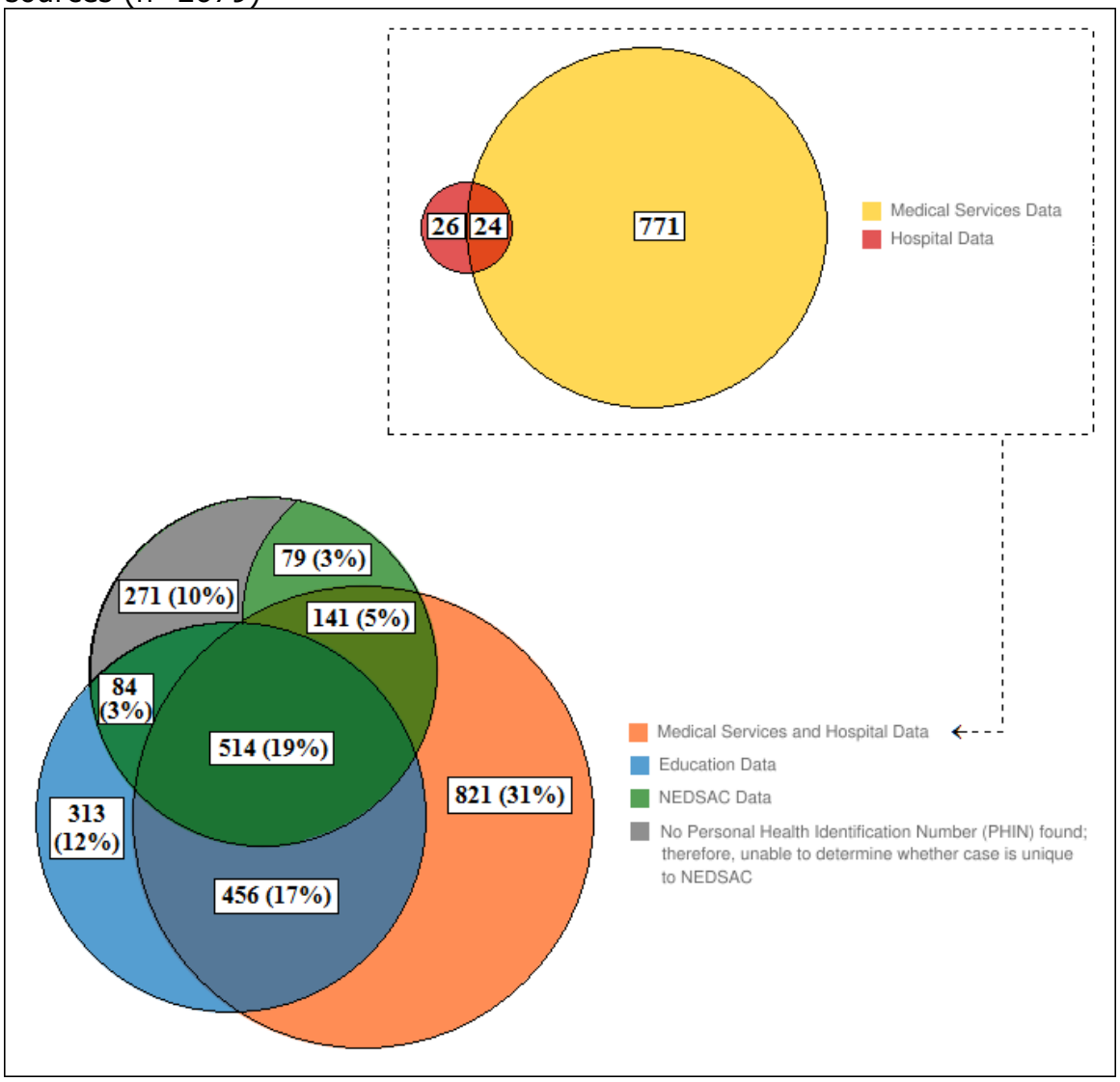


Figure 1.2 illustrates the number of cases identified in each data source. It is important to note that the 271 cases shown in gray are the ones for which Manitoba Health could not assign a Personal Health Identification Number (PHIN). Accordingly, we do not know what proportion of those 271 cases appear in the MCHP datasets used for this project and what proportion are truly unique to NEDSAC.

Outcome

A total of 2679 records formed the final study dataset (see Figure 1.2). The data elements shown in Table A1.2 (see Appendix 1) were extracted from the MCHP datasets for these records. The MCHP data analyst also prepared an expanded study dataset for 2007. The list of additional variables requested for this study year is provided in Table A1.3 (see Appendix 1).

Chapter 2: Using administrative data to evaluate the completeness of NEDSAC's case ascertainment under current protocols

When surveillance programs rely on passive case ascertainment, as the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) does, the completeness of case ascertainment depends to a large degree on the number and types of data sources used to identify cases and on the consistency of reporting by those sources (National Birth Defects Prevention Network, 2004). Moreover, in two of NEDSAC's four surveillance sites (Prince Edward Island and Manitoba) case ascertainment relies on a single source, which likely results in some children with ASD being missed (Centers for Disease Control and Prevention, 2007). Accordingly, the use of measures to evaluate the completeness of case capture is essential (National Birth Defects Prevention Network, 2004). To date, no such measures have been implemented for NEDSAC. The Public Health Agency of Canada's call in 2007 for proposals to evaluate tools and methods to enhance chronic disease surveillance provided an ideal opportunity to do so.

Under that funding call, we proposed two objectives related to the evaluation of our case ascertainment for NEDSAC: (1) To examine the completeness of NEDSAC's case capture in Manitoba and other issues related to case ascertainment, and (2) To assess whether the three-digit code of 299 in physician billing claims has sufficient specificity to "rule in" ASD. Both objectives rely on data housed at the Manitoba Centre for Health Policy (MCHP) and are described in the following sections.

Objective 1: To examine the completeness of NEDSAC's case capture in Manitoba and other issues related to case ascertainment

Children's Special Services, a program of the Manitoba Department of Family Services and Consumer Affairs that provides services to all special-needs children in the province, identifies cases of ASD to NEDSAC. Children's Special Services has seven regional offices throughout Manitoba. Staff at each office complete NEDSAC data collection forms on an ongoing basis for newly identified cases, and submit update forms when a previously identified case has moved, died, left the agency for some other reason, or has their diagnosis of ASD removed.

Although Manitoba is only one of four current NEDSAC surveillance sites, it was chosen as the focus of this objective for two reasons. First, a well-developed administrative data infrastructure exists in Manitoba, which allowed us to compare cases of ASD captured in NEDSAC with those identified in physician billing claims, hospital discharge abstracts and Education data. The second reason we decided to undertake this work in Manitoba was the low prevalence estimated through NEDSAC for that province. The most recent prevalence figures reported by NEDSAC were for 2006 (National Epidemiologic Database for the Study of Autism in Canada, 2008). At that time, the estimated prevalence of ASD among children 2–14 years of age in Manitoba was 44.6 per 10,000, or 1 in 224. Although the prevalence was not broken down for individual ages in that report, among 8–year–olds the prevalence was 66.0 per 10,000, or 1 in 152. By comparison, the Centers for Disease Control and Prevention reported a prevalence of 1 in 110 for children 8 years of age in

2006 (Centers for Disease Control and Prevention, 2009). Thus, we suspected we were underestimating the true prevalence of ASD in Manitoba[e].

In addition to evaluating the completeness of our case capture, we examined several other issues related to case ascertainment in Manitoba. These are described under Findings 2 of 3 and 3 of 3.

Finding 1 of 3: The prevalence of ASD estimated using data from NEDSAC is substantially lower than the prevalence estimated using data from the MCHP.

Table 2.1 below compares the number of ASD cases among children less than 15 years of age as of December 31 for each study year (2002–2007, inclusive) who were identified in NEDSAC and the MCHP datasets (these numbers exclude individuals living on reserves). In order to account for the possibility that NEDSAC failed to capture cases diagnosed outside the province, the count for each year of children identified in the MCHP datasets who were born in Manitoba and lived in the province continuously until the given study year was also computed.

Table 2.1. Number of Manitoban children 0-14 years of age with ASD identified in NEDSAC and MCHP datasets

	2002	**2003**	**2004**	**2005**	**2006**	**2007**
NEDSAC*	625	687	765	820	846	863
MCHP datasets†	1052	1208	1353	1488	1588	1727
MCHP datasets†: Children born in Manitoba who lived there continuously until study year‡	907	1047	1166	1285	1378	1481

NEDSAC: National Epidemiologic Database for the Study of Autism in Canada
MCHP: Manitoba Centre for Health Policy
* All prevalent cases in NEDSAC, including those for whom a PHIN could not be assigned
† Medical Services, Hospital Discharge Abstracts, and Education databases
‡ Equivalent figures are not reported for NEDSAC, as the province of birth is unknown for 402 cases.

A comparison of the estimated prevalence of ASD using data from NEDSAC and the MCHP is shown in Table 2.2. The denominator data were obtained from the Manitoba Health Insurance Registry.

[e] It is important to note, however, that the Centers for Disease Control reviews health and education records and assigns case status based on whether the child meets DSM-IV criteria for autism spectrum disorder, regardless of whether a formal diagnosis has been made (Centers for Disease Control and Prevention, 2009).

Table 2.2. Estimated prevalence of ASD per 10,000 children 0-14 years of age who resided in Manitoba during any part of the study year, based on data from NEDSAC and MCHP.

	2002	2003	2004	2005	2006	2007
NEDSAC*	28.0	30.8	34.5	37.4	38.9	39.6
MCHP datasets†	47.1	54.2	61.0	67.8	73.0	79.2
% difference	**68.2**	**76.0**	**76.8**	**81.3**	**87.7**	**100.0**
MCHP datasets†: Children born in Manitoba who lived there continuously until study year	41.2	47.7	53.1	59.2	64.1	68.7

NEDSAC: National Epidemiologic Database for the Study of Autism in Canada
MCHP: Manitoba Centre for Health Policy
* All prevalent cases in NEDSAC, including those for whom a PHIN could not be assigned
† Medical Services, Hospital Discharge Abstracts, and Education databases

Tables A2.1 and A2.2 in Appendix 2 show comparative data for the cases identified through the various MCHP databases and NEDSAC.

Tables 2.1 and 2.2 suggest that if all or most of the individuals identified with ASD in the MCHP data are true positives, NEDSAC fails to capture a substantial number of cases and thus underestimates the prevalence of ASD in Manitoba. The magnitude of the difference in prevalence estimated using data from NEDSAC and the MCHP increased steadily over the study period, from 68.2% in 2002 to 100.0% in 2007.

We had originally proposed a capture-recapture analysis of the NEDSAC and MCHP data to determine the potential extent of our under-ascertainment of ASD cases in Manitoba using the current NEDSAC protocol. However, even without such an analysis it is apparent there is a substantial difference in the number of cases identified in NEDSAC and the MCHP datasets. Furthermore, a capture-recapture analysis assumes that a) cases captured by the different sources can be accurately matched; b) the capture and recapture are independent, which, in an epidemiological context, implies independence of data sources; and c) for a given source, all cases have an equal probability of being captured (McCarty *et al.*, 1993; Harrison *et al*., 2006). Since about 25% of the cases in NEDSAC could not be assigned a Personal Health Identification Number (PHIN), and therefore could not be accurately matched to records in the MCHP datasets (see Figure 1.1), we know there is a major violation of the first assumption. Accordingly, we do not feel a capture-recapture analysis is justified at this time.

Table 2.3 compares the characteristics of cases in NEDSAC with those identified in the MCHP datasets but not in NEDSAC. A disproportionately high number of children 0–4 years of age and, to a lesser extent, children who reside in northern Manitoba (i.e., Burntwood/Churchill/Norman) were not identified in NEDSAC. The table also shows that, over the study period, a growing proportion of cases were first identified in the education data. This trend was also evident in the overall MCHP data (i.e., the MCHP data that included cases who were also identified in NEDSAC):

the proportion of cases first identified in the education data rose from 6.8% in 2002 to 20.0% in 2007 (data not shown). One possible explanation for this increase is that the Data Repository at MCHP only contains education data from 1995/96 onwards. In each subsequent year from 2002 to 2007, a growing proportion of prevalent cases would likely be diagnosed in 1995/96 or later, thus providing the potential for an increasing number of cases to first appear in the education data. Thus, the increase itself may be artefactual, and the fact that about 20% of children with a code indicating ASD are first identified in the education data is more important than the apparent temporal increase in that proportion. All children receiving special funding require a diagnosis from a recognized professional (M. Brownell, personal communication). While it is possible that a portion of this 20% comprises children who moved to Manitoba after being diagnosed elsewhere, only 12.2% of children in the overall MCHP data (and 21.5% of those who were identified in the education data only) appear to have been born outside the province (see Tables A2.1 and A2.2 in Appendix 2). It is also possible that some children first identified in the education data were diagnosed by a psychologist and therefore not captured in the physician billing data (or at least not for the initial diagnosis). This underscores the importance of including education data for estimating prevalence in jurisdictions where non-physicians also diagnose ASD.

Table 2.3. Characteristics of cases identified in NEDSAC and in the MCHP datasets who were not captured in the NEDSAC data provided to the MCHP

	2002		**2003**		**2004**		**2005**		**2006**		**2007**	
	Captured in NEDSAC											
	Yes*	No†	Yes*	No†	Yes*	No†	Yes*	No†	Yes*	No†	Yes*	No†
Total n	625	666	687	771	765	852	820	953	846	1037	863	1171
Boys (%)	494 (79.0)	510 (76.6)	546 (79.5)	591 (76.7)	612 (80.0)	656 (77.0)	662 (80.7)	729 (76.5)	685 (81.0)	796 (76.8)	701 (81.2)	905 (77.3)
Age group, years (%)												
0-4	122 (19.5)	276 (41.5)	97 (14.1)	303 (39.3)	96 (12.5)	326 (38.3)	106 (12.9)	368 (38.6)	104 (12.3)	406 (39.1)	91 (10.5)	455 (38.0)
5-9	304 (48.6)	297 (44.6)	353 (51.4)	352 (45.7)	368 (48.1)	383 (45.0)	373 (45.5)	419 (44.0)	377 (44.5)	459 (44.3)	387 (44.8)	517 (44.2)
10-14	199 (31.8)	93 (14.0)	237 (34.5)	116 (15.0)	301 (39.3)	143 (16.8)	341 (41.6)	166 (17.4)	365 (43.1)	172 (16.6)	385 (44.6)	209 (17.8)
Health region of residence‡												
Winnipeg	415 (66.4)	428 (64.3)	448 (65.2)	486 (63.0)	487 (63.7)	544 (63.8)	523 (63.8)	597 (62.6)	537 (63.5)	661 (63.7)	543 (62.9)	749 (64.0)
Central	32 (5.1)	41 (6.2)	48 (7.0)	59 (7.7)	59 (7.7)	71 (8.3)	65 (7.9)	78 (8.2)	64 (7.6)	78 (8.2)	69 (8.0)	89 (7.6)
Interlake	35 (5.6)	45 (6.8)	38 (5.5)	49 (6.4)	45 (5.9)	51 (6.0)	45 (5.5)	66 (6.9)	47 (5.6)	59 (5.7)	48 (5.6)	67 (5.7)
North/South Eastman	58 (9.3)	51 (7.7)	65 (9.5)	62 (8.0)	68 (8.9)	62 (7.2)	71 (8.7)	74 (7.7)	71 (8.4)	85 (11.0)	73 (8.5)	95 (8.1)
Assiniboine/Brandon	55 (8.8)	58 (8.7)	58 (8.4)	62 (8.0)	74 (9.7)	61 (7.2)	84 (10.2)	67 (7.1)	93 (11.0)	75 (7.2)	99 (11.5)	81 (6.9)
Parkland	18 (2.9)	17 (2.6)	19 (2.8)	22 (2.9)	20 (2.6)	23 (2.7)	19 (2.3)	27 (2.8)	20 (2.4)	27 (2.6)	20 (2.3)	33 (2.8)
Burntwood/Churchill/Norman	12 (2.0)	26 (4.0)	11 (1.6)	31 (4.1)	12 (1.6)	40 (4.7)	13 (1.6)	44 (4.6)	13 (1.7)	50 (4.8)	11 (1.3)	57 (4.9)

Table 2.3. Characteristics of cases identified in NEDSAC and in the MCHP datasets who were not captured in the NEDSAC data provided to the MCHP

	2002		**2003**		**2004**		**2005**		**2006**		**2007**	
	Captured in NEDSAC											
	Yes*	No†	Yes*	No†	Yes*	No†	Yes*	No†	Yes*	No†	Yes*	No†
Total n	625	666	687	771	765	852	820	953	846	1037	863	1171
MCHP dataset where first identified with ASD code n (%)	---	602 (90.4)	---	636 (82.5)	---	672 (78.9)	---	737 (77.3)	---	798 (77.0)	---	882 (75.3)
Medical Services		17 (2.6)		14 (1.8)		13 (1.5)		14 (1.5)		16 (1.5)		23 (2.0)
Hospital Discharges		47 (7.1)		121 (15.7)		167 (19.6)		202 (21.2)		223 (21.5)		266 (22.7)
Education												
Year first identified with ASD code												
Up to 1999	---	354 (53.1)	---	302 (39.2)	---	317 (37.2)	---	215 (22.6)	---	172 (16.6)	---	144 (12.3)
2000		89 (13.4)		78 (10.1)		6 (0.7)		63 (6.6)		59 (5.7)		51 (4.4)
2001		100 (15.0)		92 (11.9)		85 (10.0)		82 (8.6)		74 (7.1)		69 (5.9)
2002		123 (18.5)		111 (14.4)		100 (11.7)		89 (9.3)		88 (8.5)		85 (7.3)
2003		---		188 (24.4)		165 (19.4)		150 (15.7)		136 (13.1)		126 (10.8)
2004		---		---		179 (21.0)		161 (16.9)		150 (14.5)		133 (11.4)
2005		---		---		---		193 (20.3)		170 (16.4)		157 (13.4)
2006				---		---		---		188 (18.1)		178 (15.2)
2007								---		---		228 (19.5)

Finding 2 of 3: A potential data quality issue was identified in relation to updating the status of individuals whose information is in NEDSAC.

In order to produce accurate prevalence estimates, it is essential that agencies that provide data for NEDSAC notify when cases move from the catchment area or die; this ensures that those cases are not included in the numerator in subsequent years' prevalence estimates. Data from the Manitoba Health Insurance Registry revealed that 22 children (2.7%[f]) who were identified as a prevalent case in NEDSAC for a particular study year moved from Manitoba or died prior to that year. (N.B.: Of the 22 children, 10 could not be located in the Manitoba Health Insurance Registry files back to 1990, which makes it appear as though they never lived in Manitoba.)

Finding 3 of 3: Several potential data quality issues were identified in terms of including individuals in prevalence estimates for the correct study years.

Cases in NEDSAC should not be included in prevalence estimates prior to the year in which they a) first resided in the catchment area, and b) had an ASD diagnosis. NEDSAC relies on agencies to provide accurate information for this purpose. Data from the Manitoba Health Insurance Registry revealed that 12 children (1.5%[g]) who were identified as a prevalent case in NEDSAC for a particular study year only moved to Manitoba after that year.

Conversely, it is also important to ensure that cases are included in prevalence estimates from the date they first reside in the catchment area and have an ASD diagnosis. Of 272 unique cases first identified in NEDSAC in one of the study years from 2003–2007, 66 (24.3%) were identified in at least one of the MCHP datasets prior to that year.

Objective 2: To assess whether the three-digit ICD-9 code of 299 in physician billing claims has sufficient specificity to "rule in" ASD

South Eastern Ontario is another of the four NEDSAC surveillance sites. The Institute for Clinical Evaluative Sciences (ICES) is an independent, nonprofit organization that houses health services databases for the province of Ontario. The most relevant of these for the purpose of identifying cases of ASD is the Ontario Health Insurance Plan Claims Database, which contains records of physician visits and associated diagnoses, coded to the third digit of the International Classification of Diseases-9 (ICD-9) classification system. The various ASD subtypes are grouped under the 299 code with other childhood pervasive developmental disorders, such as infantile psychosis and schizophrenia, childhood type Not Otherwise Specified. (It is important to note that even if the full ICD-9 codes were available, they would still lack the specificity to precisely define ASD case status (e.g., 299.8 is the code for Asperger disorder, an ASD, but it also includes atypical childhood psychosis and borderline psychosis of childhood. The latter two conditions, as well as the other non-ASD pervasive developmental disorders, are, however, rare (see, for example, Mouridsen, 2003 and Remschmidt, 2001)).

[g] Based on records from NEDSAC where a valid PHIN was assigned by Manitoba Health.

If the work undertaken as part of this objective revealed that the 299 diagnostic code has high specificity for ASD, thus "ruling in" the diagnosis (Centre for Evidence-Based Medicine, 2009), we could partially evaluate the completeness of our case capture in South Eastern Ontario by comparing cases in NEDSAC with records that have a 299 code in the ICES data for physician visits.

Finding 1 of 1: Without further investigation, we cannot determine whether the 299 ICD-9 code has sufficient specificity to allow us to consider evaluating the completeness of NEDSAC's case capture in South Eastern Ontario using Health data from the Institute for Clinical Evaluative Sciences (ICES).

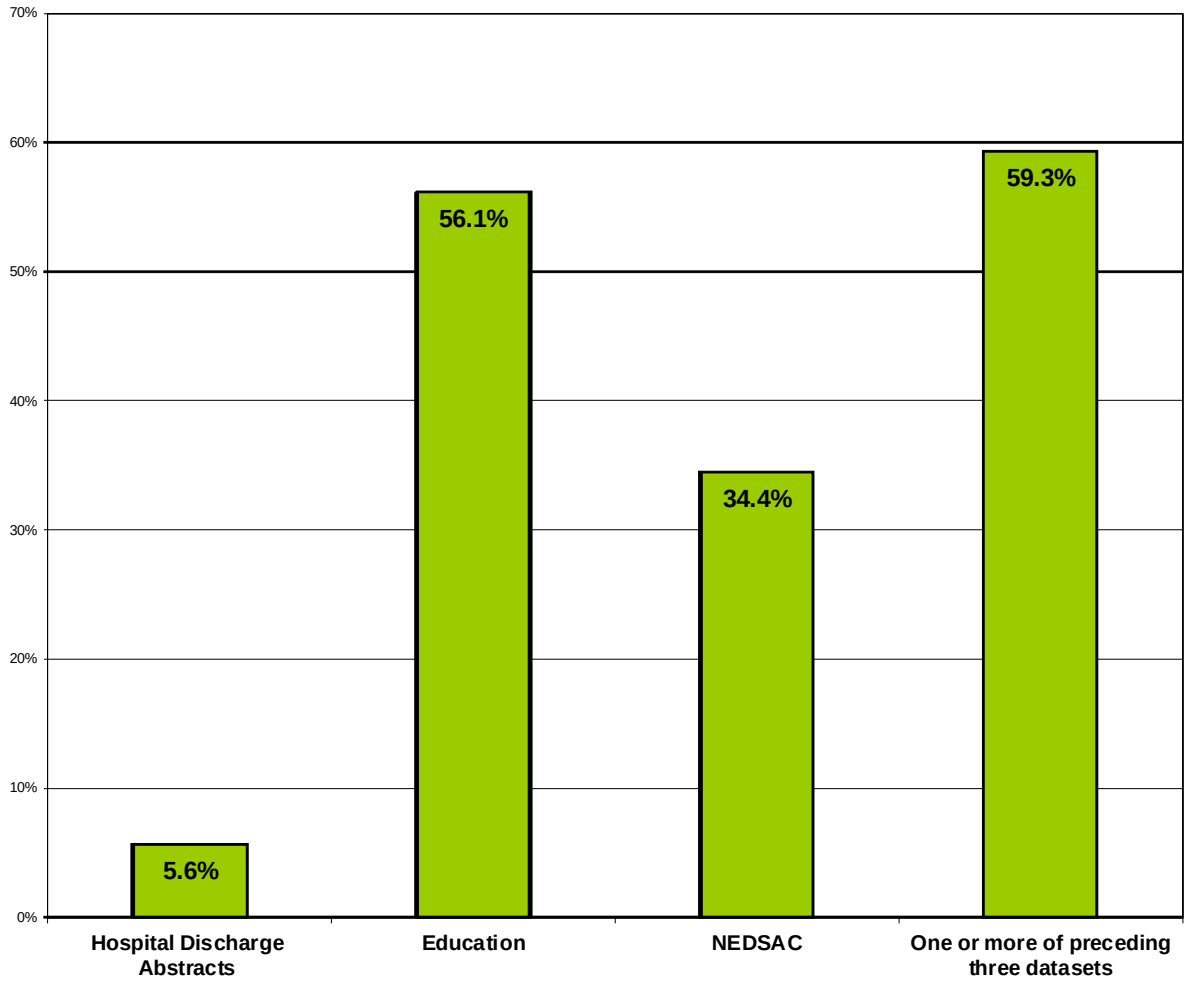
Among the 1894 records that were identified in the Manitoba Medical Services database (which contains physician billing claims, and hence only the first three digits of the ICD-9 diagnostic code), we examined the proportion that appeared in the other data sources used for this project. The results are shown in the Figure 2.1.

About 40% of the records from the Medical Services database were not identified in any of the other sources shown in Figure 2.1. A similar percentage of school-age children identified with ASD in the Medical Services database did not have an ASD code in the Education data. The high proportion of cases identified only through physician billing claims makes it difficult to determine, without further investigation, the validity of the 299 diagnostic code in terms of identifying ASD while excluding other conditions.

As stated under Objective 2, in Ontario, and Manitoba, physician billing claims only record the first three digits of the ICD-9 diagnostic code[g]; accordingly, such data may not be sufficiently specific to define ASD case status. A recent study from Nova Scotia that compared children identified with ASD in three administrative Health databases to a gold-standard clinical diagnosis found that 13 of 88 children (14.8%) without ASD who were identified solely through physician billing claims (with case status defined as one or more 299 codes) were false positives (Dodds *et al.*, 2009). Thus, while the sensitivity of that measure was low (59.7%), the specificity was fairly high (85.2%). However, it is unknown to what extent diagnostic coding patterns vary across and within jurisdictions: large variations in the accuracy of physician billing claims for identifying acute respiratory conditions were reported in a study done in Montreal (Cadieux & Tamblyn, 2008).

[g] Note that this may not be the case for all provinces and territories. For example, in Alberta physician billing claims appear to record the full ICD-9 code. See Burstyn *et al.*, 2010.

Figure 2.1. Cases of Autism Spectrum Disorders identified in the Hospital Discharge Abstracts, Education and NEDSAC databases as a proportion of the total number of ASD cases identified in the Medical Services database



Note 1: The following ICD-9 and ICD-10 codes were recorded for cases identified in the Hospital Discharge Abstracts database: 299.0 (Autistic disorder; 41.1%), 299.8 (Other specified pervasive developmental disorders;18.7%), 299.9 (Unspecified pervasive developmental disorder; 0.9%), F84.0 (Childhood autism; 15.9%), F84.5 (Asperger's syndrome; 8.4%), F84.8 (Other pervasive developmental disorders; 2.8%), F84.9 (Pervasive developmental disorder, unspecified; 12.2%).

Note 2: For the Education data, the sample was restricted to children born in 2001 or earlier.

Recommendations

Recommendation 2.1: Develop an algorithm to define ASD case status in Manitoba using administrative data.

The large discrepancy between prevalence estimates derived from NEDSAC and the MCHP data indicates a need to re-examine our surveillance methods in Manitoba. Using MCHP-held data from Health and Education, possibly supplemented with data from Children's Special Services[h], could form a viable ASD surveillance option for the province. Before implementing any such measures, however, it is critical to develop and valid an algorithm to define ASD case status using administrative data. A recent study from Nova Scotia that compared cases of ASD identified in three administrative Health databases to a gold-standard clinical diagnosis reported sensitivities ranging from 11.9% to 69.3% and specificities ranging from 77.3% to 97.7%, depending on the algorithm used to assign case status (Dodds *et al.*, 2009).

The Nova Scotia study included in the validation sample individuals who had the diagnosis of ASD confirmed (n=176) and ruled out (n=88) by the Autism Team at the IWK Health Centre in Halifax. The researchers then searched for ASD codes in records for those individuals in three provincial Health administrative datasets, and compared administrative coding to the clinical diagnosis (the gold standard) to calculate sensitivity and specificity. It is theoretically possible to adopt a similar approach in Manitoba to validate the MCHP data. For example, children seen at the Child Development Clinic in Winnipeg who had a diagnosis of ASD confirmed and ruled out could be selected, and records in the Health and Education data could then be searched for an ASD code. However, using a single site as the validation source will not tell us whether the algorithm's performance varies across different parts of Manitoba (Yiannakoulias *et al.*, 2009). Thus, an approach similar to one used by Guttmann and colleagues (2010) could be used in conjunction with the one just described. In the Guttmann study, they evaluated an algorithm based on administrative Health data from Ontario to identify cases of pediatric diabetes. All individuals less than 19 years of age who had a code for diabetes in two administrative Health databases (physician billing claims and hospital discharges) were identified. From that pool, individuals who had been hospitalized at any of the five hospitals chosen as the validation sites were identified and 700 of those individuals were randomly selected. A further 300 individuals with no record of

[h] Some considerations regarding the use of these data include the following: 1) Although we can only be certain that 3% of the cases in the study dataset were unique to NEDSAC (see Figure 1.2), the inclusion of Children's Special Services as a data source could form, with data from Health, a multiple source ascertainment strategy in the younger age group (who wouldn't appear in the Education data until they start school); and 2) If we continue to use Children's Special Services as a data source, what would be the best method to obtain those data? Would the agency continue to identify cases to NEDSAC, in which case we would have to follow the same procedure outlined in Chapter 1 to link those data to the health and education data (and would have to decide how to treat the cases that don't link to a PHIN in the analysis)? Or could the Children's Special Services data be transferred to the MCHP Data Repository on an annual basis like other datasets from Manitoba Family Services and Consumer Affairs?

diabetes in the administrative Health data, who were hospitalized at one of the five study hospitals, were also selected. Trained abstractors then conducted a chart review for the validation sample (n=1000) to search for evidence of diabetes, which was considered the gold standard for the purposes of calculating sensitivity and specificity.

Conducting a validation study would also clarify how well the 299 diagnostic code in physician billing claims captures ASD, although, as stated previously, patterns of diagnostic coding may differ across and within jurisdictions. If a validation study is undertaken, it might be useful to compare the sensitivity and specificity of physician billing claims for identifying ASD in Manitoba to what was obtained in Nova Scotia (Dodds *et al*., 2009).

It is currently unknown whether there is any way to validate the status of individuals identified only in the Education data (12% of the total study dataset; see Figure 1.2).

Recommendation 2.2: Determine whether the date an ASD code first appears in Health, and, if possible, Education data at MCHP accurately reflects the date of diagnosis.

Ascertaining whether the date an ASD code first appears in the MCHP data accurately reflects the date of the initial ASD diagnosis is important for a number of reasons. First, it would allow an age at diagnosis to be calculated. This was identified as a high-priority indicator for ASD surveillance in Canada (see Chapter 3). Moreover, it would be helpful to monitor age at diagnosis to better interpret changes in prevalence among younger age groups. For example, a Danish study that compared the prevalence of ASD in two birth cohorts of three-year-olds reported that at least 66% of the apparent increase in prevalence could be due to changes in the age at diagnosis that occurred between the two time periods (Parner *et al*., 2008). An accurate year of initial diagnosis is also required to report incidence, as measured by the number of new cases of ASD diagnosed in a year[i]. Finally, an accurate date of diagnosis would ensure that cases are included in the numerator for the correct study years. For example, if a child is initially diagnosed with ASD in 2004 but an ASD code first appears in the administrative data in 2005, that child would only be included in prevalence estimates from 2005 onwards. However, they should appear in the numerator for 2004 as well.

[i] Note that this may not be a good measure of risk. As one investigator states, "Measuring incidence *rates* requires clearly identifiable incidence *times.* With respect to autism, many researchers have conflated time of onset with time of detection…" (Blaxill, 2004).

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Chapter 3: Priority indicators for autism spectrum disorders surveillance captured in the Manitoba Centre for Health Policy Datasets

On November 8, 2007, a group of clinicians and researchers from across Canada who work in the field of autism spectrum disorders (ASD) met in Toronto for a one-day workshop. The goal of that workshop was to identify, from a national perspective, information needs, data source options, and system models to enhance autism surveillance in Canada (Developmental Consulting Program, 2007). During the workshop, priority indicators for autism surveillance were selected based on their public health importance, feasibility in terms of data collection, and data quality. Many of the selected indicators are not currently collected in the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC, www.nedsac.ca), which contains basic demographic and diagnostic information only.

Objective: To explore indicators for ASD that can be captured in the MCHP datasets

As part of the proposal submitted to the Public Health Agency of Canada for evaluating tools and methods to enhance chronic disease surveillance, we proposed to explore which of the ASD priority indicators selected at the 2007 workshop can be collected through the Manitoba Centre for Health Policy (MCHP) datasets, and to examine data quality issues (e.g., missing values) for those indicators.

Finding 1 of 3: Using the MCHP data would expand the list of reportable indicators considerably.

Table 3.1 provides a list of factors identified by participants at the 2007 workshop as priority indicators for ASD surveillance. Beside each indicator are columns indicating whether that factor is currently collected in NEDSAC and whether it can be captured in the MCHP datasets. For indicators that are captured in NEDSAC and the MCHP datasets, the percent of missing values, based on 2007 data, is provided where applicable. MCHP data values for the indicators marked with an asterisk are available in Table A2.3 in Appendix 2.

Table 3.1. Priority indicators identified at the 2007 technical workshop on surveillance information needs and options for autism spectrum disorders, and availability of those indicators in the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) and Manitoba Centre for Health Policy (MCHP) datasets

Indicator	Currently collected in NEDSAC?	Available in MCHP datasets?	Additional notes
Incidence in children	No, if measured as number of new diagnoses per year	Potentially (see table footnote a)	Need to define "incidence". See Blaxill, 2004.
Prevalence in children and adults	Diagnosed prevalence is available for children under 15 years of age	Yes (diagnosed prevalence only)	
Individual factors			
Ethnicity, including Aboriginal status	Yes; but 24.2% missing data	First Nations and Métis identifiers are available at the individual level. Information on other ethnicities is not available.	Permission from the Assembly of Manitoba Chiefs and the Manitoba Métis Federation are required for use of these identifiers.
Sex	Yes; 100% data	Yes; 100% data	
Comorbidities	No	Yes, for conditions with an ICD code	See Section 5.2.2 for cautions about the use of ICD codes to measure comorbidity.
Developmental functioning	No	No	

Indicator	Currently collected in NEDSAC?	Available in MCHP datasets?	Additional notes
Severity of disability (intelligence, language, behaviour, adaptive behaviour)	No	Only to a very limited degree (see note at right)	Diagnostic codes for intellectual disability are available. A higher level of special education funding (see *School supports*) indicates a higher level of disability.
Longer-term social and other outcomes			
School attendance	No	Yes	
School supports	No	Yes	Can determine in MCHP data whether special education funding was received, and what level (II-III).
Life expectancy	No	Potentially (see note at right)	Adequate numbers of cases and years are required to measure life expectancy.
Criminal activity	No	Not currently	The MCHP is in negotiations with the Department of Justice to obtain these data.
Independent living	No	Yes	The MCHP data can be used to determine if an individual lived in a personal care home, and whether he or she received home care supports.
Employed	No	No	
Adults in daily activity programs, pensions	No	No	
Receiving social assistance	No	Yes	

Indicator	Currently collected in NEDSAC?	Available in MCHP datasets?	Additional notes
Economic burden	No	Potentially (see note at right)	Could possibly be measured based on health care utilization
Family Factors			
Family socio-economic status	No	A crude measure of income is available at the individual level (see note at right). Neighbourhood measures are also available; 1.5%–3.6% missing data for the latter.	At the individual level, a dichotomous variable is available from 1995 to indicate whether a family received social assistance (see *Receiving social assistance*).
Affected siblings	Yes; 18.1% missing data	Yes. Note that for 2.2% of cases born in Manitoba a link between the child and mother could not be made.	For children born outside Manitoba, family membership can be established using the Family Registration Number (see Finding 2 of 3). However, there is no assurance that family members are biologically related.
Maternal age	Yes; 75.4 % missing data	Yes; but 14.2% missing data (4.6% if child born in Manitoba)	See additional notes for *Affected siblings*.
Paternal age	Yes; 83.0% missing data	No (see note at right)	Children cannot be reliably linked to their biological fathers using the MCHP data.
Mental health among family members	No	Yes, for those clinically diagnosed.	See additional notes for *Affected siblings*.
Migration	No	Yes	Can use the MCHP data to track movements within and to and from province.

Indicator	Currently collected in NEDSAC?	Available in MCHP datasets?	Additional notes
Marital status of parents	No	Yes, but see note at right	Marital status can be identified through the Manitoba Health Insurance Registry. Changes to marital status that are not registered with Manitoba Health (i.e., sending a notice about change of status) will not be entered in the Registry. See Section 5.2.2.
Diagnostic Factors			
Age at diagnosis	Yes; 15.1% missing data	See Recommendation 2 in Chapter 2.	
Contact sequence (suspected, referral, initial, diagnosis)	Very limited information available. NEDSAC collects information on initial and current ASD diagnoses.	No	
Type of treatment/services (medication, respite, complementary medication, wait times, intensity)	No	Only information on prescription medication is available.	
How the diagnosis is made	Yes (what types of professionals made the diagnosis and tests that were used); 71.3% missing data	Yes	The diagnosing professional (e.g., family physician, pediatrician) can be established through the Medical Services database.

Indicator	Currently collected in NEDSAC?	Available in MCHP datasets?	Additional notes
Change in diagnosis over time	No	No	This may no longer be relevant once DSM-V is published. Diagnostic subtypes will likely be eliminated.
Risk Factors			
Obstetric factors, including infertility treatment*	No	Some information available, e.g., presentation, delivery, prenatal care, fertility treatment, etc.	
Immunization	No	Yes; 0.2%–0.6% missing data (no missing data for those who were born in Manitoba and lived there up to 2007).	
Neighbourhood	Residence is only available to first three digits of postal code; 1.0% missing data	Residence is available to level of full postal code; 1.5%–3.6% missing data	
Environmental	No	Potentially (see note at right)	Could be measured if looking at ecologic measures for neighbourhood; would need to link geographical area to environmental measures in external datasets.

[a] If this indicator is based on when the child is diagnosed, then it could potentially be captured in the MCHP data. See Chapter 2, Recommendation 2, and footnote 'j' regarding incidence.

Finding 2 of 3: There are several potential and known data quality issues related to capturing certain indicators in the MCHP data.

Certain indicators, such as comorbidities, can be captured in the MCHP data if they have a corresponding ICD-9 or ICD-10 code. However, the accuracy of that coding has not, in many cases, been validated. A report documenting the validity of the MCHP's administrative Health data (hospital discharge abstracts, physician billing claims and prescription drug records) for measuring the prevalence of chronic conditions was published in 2008 (Lix *et al.*, 2008). The sensitivity and specificity of the algorithms varied widely depending on the condition. For example, the algorithm to identify diabetes demonstrated a sensitivity of 94.4% and a specificity of 97.2%. In contrast, the algorithm to identify rheumatoid arthritis only demonstrated a sensitivity of 14.4% (although the specificity was 99.3%). Thus, measuring comorbidity in this way may substantially underestimate the prevalence of certain conditions.

Measuring indicators at the family level (e.g., obstetric factors, mental health of other family members) depends on the ability to link children with biological parents and biological siblings. Linking children born in Manitoba to biological mothers (and to siblings from the same mother) is fairly straightforward through hospital birth and obstetric records, although in a small proportion (2.2%) of cases a mother-baby link could not be established (see Table A2.3 in Appendix 2). Establishing biological paternity, both for children born in and outside the province, and biological maternity for children born outside Manitoba, is less reliable. In the Manitoba Health Insurance Registry, family members are assigned a Family Registration Number. However, individuals with the same Family Registration Number are not necessarily biologically related (e,g., children from blended families may share the same Family Registration Number but have different biological mothers or fathers, or both).

Other indicators have specific data quality issues. For example, recent data from the Manitoba Health Insurance Registry indicates that about half of mothers were married at the time of their child's birth (see Table A2.3 in Appendix 2). The actual figure is believed to be closer to 80% (L. MacWilliam, personal communication, April 22, 2010).

Finding 3 of 3: There are some indicators currently collected in NEDSAC that may not be available in the MCHP data.

NEDSAC collects information on several variables important to the epidemiology of ASD that may not be easily captured in the MCHP data. The first of these is age at diagnosis. There is a general consensus among the scientific community that early diagnosis is essential to achieve optimal outcomes (Harris & Handleman, 2000; Dawson, 2008; Centers for Disease Control and Prevention, 2007). Accordingly, monitoring trends in the age at diagnosis should be considered an important function of an ASD surveillance program. A second and compelling rationale for monitoring trends in age at diagnosis is that any changes may affect, and therefore partially explain, changes in prevalence (Centers for Disease Control and Prevention, 2009; Parner et al., 2008), particularly if one is conducting surveillance

among younger age groups.

Another variable available through NEDSAC (though incomplete) relates to ethnicity. Information on ethnicity is limited in the MCHP data. First Nations and Métis identifiers are available at the individual level. These are potentially important, since two Canadian studies suggest that ASD is under-represented among Aboriginal children (Ouellette-Kuntz *et al*., 2006; Burstyn *et al*., 2010). This population may also experience diagnostic delays (Burstyn *et al*., 2010). However, as indicated in Table 3.1, permission from the Assembly of Manitoba Chiefs and the Manitoba Métis Federation, respectively, are required to access these identifiers. Information on other ethnicities is not available at the individual level in the MCHP data.

Recommendations

Recommendation 3.1: Re-evaluate which indicators should be collected as part of an ASD surveillance program using administrative data.

Although a large number of priority indicators for ASD surveillance were identified at the 2007 workshop, it may not be feasible, or desirable, to collect all of these as part of ongoing or periodic surveillance. Some indicators, such as comorbidities, may be better captured in a well-designed research study. A review of existing ASD surveillance programs in other countries (e.g., Autism and Developmental Disabilities Monitoring Network in the United States (Centers for Disease Control and Prevention, 2007); Western Australia Register for Autism Spectrum Disorders (Glasson, 2002)) could form a starting point for deciding which indicators should be collected to allow for international comparisons.

For those indicators that are deemed necessary for ASD surveillance, some may not be well captured in administrative datasets (e.g., age at diagnosis, ethnicity). It may be necessary to implement a hybrid surveillance model where some information is collected by alternate means, such as chart review.

Recommendation 3.2: Develop a protocol for access to indicators that can be accurately captured in the MCHP datasets.

MCHP datasets capture diagnostic information for autism spectrum disorders, as well as comorbidities. However, the accuracy of the coding has not, in many cases, been validated. It is true for diagnoses of autism spectrum disorders. As a consequence, the developed protocol would be dependent on having first established a valid algorithm to identify cases (as per Recommendation 2.1).

MCHP datasets also capture:

- demographic information (sex, postal code),

- medical information (health services utilization, immunization),

- school attendance and supports,

- independent living support (living in a personal care home, receiving home care supports),

- information on individuals receiving social support

- family information (socio-economic status, affected siblings, maternal age, mental health among family members, migration, marital status of parents).

See Table 3.1 for details.

In order to use such data for ongoing surveillance agreements would need to be developed with MCHP as well as Manitoba Health, Manitoba Education and Manitoba Family Services and Consumer Affairs.

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PART 2: Expanding Surveillance of ASD in Canada

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC, www.nedsac.ca) aims to estimate the prevalence of autism spectrum disorders (ASD) using service provision and administrative data (collated from education and clinical sources) from various provinces or regions (Prince Edward Island, Newfoundland and Labrador, South Eastern Ontario and Manitoba, and originally from Calgary and British Colombia). By adding more regions to our surveillance program, we will be able to more fully characterize the epidemiology of ASD in Canada. We explored the feasibility of expanding surveillance activities to other regions or provinces. We identified Ontario, Quebec, Alberta and British Colombia as priority areas. A previous report submitted to the Public Health Agency of Canada in 2008 described these provinces as having the capacity to conduct ASD surveillance using administrative data (Ouellette-Kuntz & Brown, 2008).

In densely populated regions, the most efficient method for conducting surveillance of ASD is to use administrative datasets. Ideally, multiple sources would be used to ascertain children who have an ASD, including educational datasets, information on children enrolled in provincial early intervention programs, and Health data. In small regions or sparsely populated areas, the current NEDSAC protocol is viable. Data holders in Prince Edward Island, Newfoundland and Labrador are confident that they capture most of the children diagnosed with ASD (See Appendix 3).

To examine the feasibility of expanding surveillance of ASD to other regions and provinces, we completed the following series of activities: (1) identifying sources of data from multiple sectors relevant to the surveillance of ASD; (2) understanding and describing the process required to access the datasets held by those sources; and (3) determining the feasibility of linking identified datasets, including the availability of personal identifiers to link data for a specific individual across several data sources. We also explored the process required to obtain permission to access and link data sources.

Chapter 4: Expanding surveillance of ASD in Ontario

In Ontario, NEDSAC only collects data in the southeast region. This chapter presents data sources that would allow surveillance activities at a provincial level.

Sectors providing supports to children with ASD and their families

Four government departments provide supports to children with ASD and their families in Ontario and collect information to support the administration of their programs. Some diagnostic and clinical services are provided by the Ontario Ministry of Health and Long Term Care. A range of autism intervention services (including early intervention programs) are administered through the Ministry of Children and Youth Services. Publicly funded elementary and secondary schools are administered by the Ministry of Education. Finally, some residential and other specialized programs for children with developmental disabilities, including ASD, are provided by agencies funded by the Ministry of Community and Social Services.

Activities completed

In South Eastern Ontario, NEDSAC is identifying cases through local school boards, the regional early intervention program, and one diagnostic centre. As such, for Ontario, NEDSAC does not provide data at a provincial level and, in the catchment area, not every sector that provides supports to children with ASD collaborates with NEDSAC.

Ontario has a repository for population health data: the Institute for Clinical Evaluative Sciences (ICES; www.ices.on.ca). In the Fall of 2010, Hélène Ouellette-Kuntz became an ICES scientist and Virginie Cobigo an ICES fellow. That allows them to become familiar with data available at ICES and their validity. We have reviewed documents and consulted with key informants to better understand the process to access ICES data and to link ICES data with other datasets.

Data sources

The Institute of Clinical Evaluative Science (ICES, www.ices.on.ca) is an independent, nonprofit organization that houses health services databases for the province of Ontario and carries out population-based health services research. ICES has the ability to anonymously link population-based health information at the individual level. Only ICES scientists (or collaborators of ICES scientists) can access ICES data from one of the four sites (two in Toronto, one in Kingston/Queen's University and one in Ottawa).

Table 4.1 shows data available at ICES and potentially relevant to the surveillance of ASD. The most relevant ICES database for the purpose of identifying cases of ASD is the Ontario Health Insurance Plan Claims Database, which contains records of physician visits and associated diagnoses, coded to the third digit of the ICD-9 classification system. The various ASD subtypes are grouped under the 299 code with other childhood pervasive developmental disorders, such as infantile psychosis and schizophrenia, childhood type NOS. (It is important to note that even if the full ICD-9 codes were available, they would still lack the specificity to precisely define

ASD case status (e.g., 299.8 is the code for Asperger disorder, an ASD, but it also includes atypical childhood psychosis and borderline psychosis of childhood. The latter two conditions, as well as the other non-ASD pervasive developmental disorders, are however rare (see, for example, Mouridsen, 2003 and Remschmidt, 2001)). As presented in Chapter 2 of this report, without further investigation, we cannot determine whether the 299 ICD-9 code in physician claims has sufficient specificity to "rule in" ASD.

ICES provides some capacity for surveillance activities using administrative datasets. However, linkages with other datasets is advisable since ICES only has health information. Relevant information on children with ASD might be held by the Ministry of Children and Youth Services, the Ministry of Education, and the Ministry of Community and Social Services.

Table 4.1. ICES data relevant to the surveillance of ASD

	Variable of Interest	**Data Source(s)**	**Description**
About the child with ASD	Sex	RPDB	Sex coded as M/F
	Date of birth: year of birth & age category	RPDB	Birth date (level 1 users) or birth year (level 2 users)
			Age at the specified date, either calculated from birth date (level 1 users) or estimated as of July 1st of birth year (level 2 users)
	Date of death: year died	RPDB	Date of death (missing value if there is no death)
	Address: health region of residence	RPDB	Local Health Integration Network for most recent geographic data at specified date
	Place of birth: whether born in Ontario	RPDB	OHIP eligibility indicator at a specified date; values = ., 0, 1 *(determine if individual is eligible for OHIP coverage at birth date)*
	Date moved to province: year moved to Ontario	RPDB	Date of the start of OHIP eligibility period *(3 month waiting period for start of OHIP coverage)*
	Date moved out of province: year moved out of Ontario	RPDB	Date of the end of OHIP eligibility period

	Variable of Interest	Data Source(s)	Description
About the child with ASD	ASD diagnosis* ASD diagnosis source ASD diagnosis year *ICD-9: 299, 299.0, 299.1, 299.8, 299.9 ICD-10: F84.0, F84.1, F84.2, F84.3, F84.4, F84.5, F84.8, F84.9	OHIP	Diagnosis code – main reason patient saw physician
			Date on which service was performed
		NACRS	dx10code1 is the main problem for visit; dx10code[2-10] are the other problems that affect care
			Date visit completed
		DAD	Diagnosis code – dx10code since 2002 to reflect change from ICD-9 to ICD-10
			Discharge date
	Other diagnoses* Other diagnoses year *ICD-9: 237, 290-298, 300-319, 343, 345, 758-759 ICD-10: F00-F83, F85-F99, G40-G41, G80, Q80-Q99	[same data sources as ASD diagnoses]	
	Level of special education funding	Not available	
	Whether or not attending school	Not available	
	Whether or not receiving income support	Not available	
	Whether or not childhood vaccines have been received as per schedule *Up-to-date immunization status at age 2 defined as having had 5 immunizations* Definition from: Guttman et al. (2006)	OHIP	G538: immunization given in the context of a visit for other care G539: immunization is the sole reason for visit
	Neighbourhood SES	RPDB	Geographic information for different geographic levels at a specified date
		Census	Total, median, average income for geographic region
	Whether or not lives in personal care home	Not available	
	Whether or not receiving Home Care supports	Not available	

	Variable of Interest	Data Source(s)	Description
	Whether or not lives in a lone parent household	Not available	
About family members	Maternal Age (at birth of child)	Mother: MOMBABY	Mother's age at admission (from CIHI/DAD)
	Marital Status	Not available	
	Whether any siblings have an ASD	Not available	
	Whether any obstetrics complications arose in relation to the case with ASD	OHIP, NACRS, DAD	
	Whether or not mother received prenatal care in relation to the case with ASD *Mother identified from MOMBABY*	OHIP	
	Whether any family member (parents or siblings) has a mental health problem	Not available	

Notes relative to Table 4.1:
The highlighted sections are the variables of interest that do not have any data available. The variables of interest that have two asterisks beside them are those that can potentially be derived from ICES data.
RPDB: Registered Persons Database (5 files: rpdbdemo, rpdbelig, rpdbpstl, pstlyear, contactYYYY)
OHIP: Ontario Health Insurance Plan claims database
NACRS: National Ambulatory Care Reporting System
CIHI: Canadian Institute for Health Information
DAD: Discharge Abstract Database
MOMBABY: Mother-Baby Linked Database (ICES-derived)
Census: 2006 Census Area Profiles available at 8 geographic levels (DA: dissemination area, FSA: forward sortation area, CSD: census subdivision, CD: census division, CT: census tract, CMA: census metropolitan area, UA: urban area, DPL: designated place)

Data linkages

The first step would be to establish data sharing agreements between ICES and other relevant entities (Ministries of Education, Children and Youth Services, and Ministry of Community and Social Services) to allow linkage between administrative Health data and the other entities' datasets. Such data sharing agreements require

that both a Privacy Impact Assessment (PIA) and a Threat Risk Assessment (TRA) be conducted. Privacy officers emphasize that the process of completing a PIA (and its underlying rationale) is something that many scientists and decision makers do not understand well. It is important to stress that although a PIA is not required in law, it is a privacy best practice.

ICES has prior experience working with ministries outside of the Ministry of Health in creating linked data for research purposes. One such study involved linking Health data with information from the Ministry of Transportation on motor vehicle accidents involving elderly Ontarians. The process of preparing a data sharing agreement between ICES and that Ministry took over one year. Based on that project, ICES has created a template that could be modified to meet the needs of other projects and has advised us to allow between 1 and 2 years for the necessary PIA, TRA, and data sharing agreements to be completed.

For a data sharing agreement to be established, data holders must be involved from the beginning of the process. Strong collaborations among researchers or those undertaking surveillance and data holders are crucial early on and throughout the surveillance activity.

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Chapter 5: Expanding surveillance of ASD in Quebec

Québec is not one of NEDSAC's catchment areas. Because of current collaborations among NEDSAC researchers and service providers in this province, as well as our awareness of potential sources of data, we aimed to determine the feasibility of accessing relevant data sources.

Sectors providing supports to children with ASD and their families

In Quebec, three government departments provide supports to children with ASD and their families. Diagnostic and clinical services are administered by the *Ministère de la Santé et des Services sociaux*, including rehabilitation supports specific to autism delivered by the *Centres de réadaptation en déficience intellectuelle et troubles envahissant du développement* (CRDITED; n=20). Publicly funded elementary and secondary schools are administered by the *Ministère de l'Éducation, du Loisir et du Sport*. In addition, the *Régie des rentes du Québec* (RRQ) provides financial support (the Supplement for Handicapped Child) for all families of children with disabilities, including an ASD. The *Régie des rentes du Québec* is administered by the *Ministère de l'Emploi et de la Solidarité sociale (MESS).*

Activities completed

In April 2009, Virginie Cobigo received a postdoctoral award from the *Fonds de recherche en santé du Québec* (FRSQ) to study data available in administrative databases in Québec relevant to a better understanding of ASD and intellectual disabilities (under the supervision of Hélène Ouellette-Kuntz and Duncan Hunter, Queen's University). The award, originally offered for the period April 1, 2009 to March 31, 2011, was renewed for an additional year (April 1, 2011 to March 31, 2012).

As a postdoctoral fellow, Dr. Cobigo has consulted with key informants and established collaborations with data holders from the *Ministère de l'Éducation, du Loisir et du Sport, Ministère de la Santé et des Services sociaux,* and the *Ministère de l'Emploi et de la Solidarité sociale.* She also approached several *Centres de réadaptation en déficience intellectuelle et troubles envahissant du développement* (CRDITED).

In April 2010, Dr. Cobigo was granted fellow status at the *CRDITED Mauricie-Centre-du-Québec, Institut universitaire*. As a fellow, she was authorized to access data contained in the database of the CRDITED Mauricie-Centre-du-Québec, Institut universitaire. A month later, the CRDITED Mauricie-Centre-du-Québec, Institut universitaire authorized the research project "Feasibility study of a surveillance system for Pervasive Developmental Disorders in Québec" (*Étude de faisabilité d'un système de surveillance des troubles envahissants du développement au Québec*). Subsequently, ethics approval was obtained from the Joint Ethics Committee of the CRDITED (*Comité d'éthique de la recherche conjoint destiné aux CRDITED, www.cerc-crdited.ca; #* CERC-0081) and from the Queen's University Research Ethics Board (Study code: EPID-320-10).

On November 1, 2010, a grant application was submitted to the Canadian Institutes of Health Research (CIHR), Partnership for Health System Improvement Program to develop a ASD surveillance program in Quebec using administrative data (Applicants: C. Dionne, V. Cobigo, H. Ouellette-Kuntz *et al.*). The project, titled: *Partenariats Chercheurs - Décideurs pour l'amélioration des services aux enfants présentant un trouble envahissant du développement*, received support from Lyne Jobain, *Ministère de la Santé et des Services sociaux, Direction générale de la santé publique*, as well as Denis Roy, *Institut de santé publique*, *Vice-président aux affaires scientifiques*. This project was, however, not recommended for funding at CIHR.

Data sources

In Quebec, health information is aggregated at the *Régie de l'assurance maladie du Québec* (RAMQ). The RAMQ administers the public health and prescription drug insurance plans: it informs the public, manages the eligibility of persons, remunerates health professionals and ensures the secure flow of information (www.ramq.gouv.qc.ca). RAMQ datasets contain demographic information on each individual covered by the provincial health insurance plan, the use of medical services and hospitalizations on an individual basis, as well as some diagnostic information. The RAMQ provides statistical information to the public, health professionals and decision-makers. Although it makes population-based health information available to researchers, it does not have a research mandate. Approval from the RAMQ is required to access its data.

The *Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement* (CRDITED) share a database containing information on their clientèle. In 2007, they provided services to about 30 000 persons; about 5000 of these were children and adults with an ASD. The *Système d'information clientèle: Déficience intellectuelle* (SICDI) is now replaced by the *Système d'information pour les personnes ayant une déficience* (SIPAD). Approval from each CRDITED is required to access data (through the *Direction des services professionnels*).

The *Ministère de l'Éducation, du Loisir et du Sport* (MELS) also has a dataset relevant to the surveillance of ASD. It contains information on school attendance and support required at school. Approval from the MELS is required to access data. At this time, we are only aware of aggregated data being made available to agencies outside MELS.

The *Régie des rentes du Québec* (RRQ, *Ministère de l'emploi et de la solidarité sociale, MESS*) provides financial support for all families of children with disabilities. A database contains information on all families receiving the Supplement for Handicapped Child. Discussions with key informants revealed that about 5000 children with ASD are recorded in their dataset. Approval from the MESS is required to access these data.

In addition to approvals from the data holders, in Quebec, approval from the *Commission d'accès à l'information* is also required to assure that data privacy and confidentiality are protected. The *Commission d'accès à l'information* is responsible

for administering access to documents held by public bodies and the protection of personal information. A complete list and description of studied variables is required before submitting a project to the *Commission d'accès à l'information*, as well as detailed information about data linkages and management.

To our knowledge, only aggregated data from MELS have been used for the purpose of surveillance of ASD in select regions of the province (Noiseux, 2009, 2011). Table 5.2 describes data available through the different datasets relevant to ASD surveillance in Quebec.

Data linkages

The *Système d'information clientèle: Déficience intellectuelle* (SICDI) contains unique Health Insurance Numbers, which makes it technically feasible to link to Health datasets. The new system in place (SIPAD) is also supposed to contain Health Insurance Numbers, which are crucial for accurate linkage.

According to our key informants, linkage between educational datasets and the dataset held by the *Régie des rentes du Québec* have been tried. However, no information on the success of the linkage is available.

In Quebec, linkages between datasets must be conducted by the *Régie de l'assurance maladie du Québec*, which will remove any identifiers before sending the data to the researchers.

Table 5.1. Data sources in Québec

Variable	**Availability**			
	SICDI	**RAMQ**	**MELS**	**RRQ**
Prevalence	All (administrative prevalence).			
Incidence	All, if possible to identify new cases each year.			
Life expectancy	Date of death available but number of cases too small		No	Date of death available but number of cases too small
Sequence of diagnosis	No	Yes	No	Yes
Waiting time	Time between admissibility and first service provided	No	No	Time between application and payment of the *Supplément pour enfants handicapés*, for each child.
Age at diagnosis	No	Yes	Yes	Yes
How the diagnosis is made	No	Health services used before the diagnosis	No	No
Ethnicity	No	No	Maternal	No

Variable	Availability			
	SICDI	RAMQ	MELS	RRQ
			language only	
Sex	Yes	Yes	Yes	Yes
Intellectual and adaptative functioning	Intellectual disability Yes/No	No	No	No
School attendance	No	No	Yes	No
Support at school	No	No	Yes	No
Comorbidities	Yes: Intellectual disability, behaviour disorders and some health disorders	Yes	No	No
Social assistance	No	Yes	No	Supplément pour enfants handicapés.
Daily activities	Yes, including Intensive behavioural Interventions	No	No	No
Independent living / residential services	Yes: with family or in a residence	No	No	Yes: with family or placement
Siblings with ASD	No	No	No	Yes
SES	No	Deprivation index (neighbourhood)	Yes	No
Migration	If moved out of province: reason for closing the file. If moved within the province, information might be available from another CRDITED.	Whether moved out of province	No	No
Obstetric factors	No	Yes if linkage	No	No

Variable	Availability			
	SICDI	RAMQ	MELS	RRQ
		possible with the mother's file.		
Vaccination	Some (ex.: flu)	No	No	No
Neighbourhood (place of birth)	No	Deprivation index	Place of birth only	No
Age of parents	No	Yes if linkage with parents' files possible	No	Yes
Marital status	No	No	No	Yes
Mental health disorders in the family	No	No	No	No
Environnmental exposure	No	No	No	No

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Chapter 6: Expanding surveillance of ASD in Alberta and British Columbia

Alberta is not one of the current NEDSAC catchment areas. However, this province offers opportunities to develop ASD surveillance because of the newly established Child and Youth Data Laboratory, Alberta Centre for Child, Family and Community Research (www.research4children.com).

British Columbia was a NEDSAC catchment area at its inception, but data collection was stopped because of concerns related to case identification. Since then, the Provincial Health Services Authority has established the British Columbia Autism Assessment Network (BCAAN). BCAAN is responsible for assessing and diagnosing children who may have autism across the province. BCAAN offers promising opportunities for ASD surveillance as the network applies standardized approaches to assessment and diagnosis and shares a dataset.

In May 9th, 2011, we organized a workshop on the surveillance of ASD in Canada. From Alberta, we invited Dr. Xinjie Cui, Director of the Child and Youth Data Laboratory. From British Columbia, we invited Dr. Stephen Wellington, Medical Director, BCAAN, as well as Karen Kalynchuk, Program Director, BCAAN. The following information is based on their presentations at the workshop.

Foreseeable opportunities in Alberta

In Alberta, the Ministry of Child and Youth Services administers services and supports for children with disabilities and their families. It holds information on services provided to children with ASD and their families, but it is likely to identify predominantly cases with disabilities that significantly limit their ability to function in normal daily living activities and who need specialized supports.

As in all Canadian provinces, Alberta has a publicly administered and funded health care system that guarantees Albertans receive universal access to medically necessary hospital and health care services. All new and returning Alberta residents must register for Alberta Health Care Insurance Plan (AHCIP) coverage to receive insured hospital and physician services. Alberta Health and Wellness holds population-based Health data, including physician claims, hospital discharge and ambulatory care. A three-digit ICD code (299 code) is used to identify children with ASD in these databases.

The Ministry of Education administers schools from early childhood services to Grade 12. The Ministry of Education has no code for ASD. Their coding system is based on the impact of the disability or condition on the child's daily functioning.

Dr Xinjie Cui listed two autism follow-up clinics: the Glenrose Rehabilitation Hospital and the Children's Hospital. Autism follow-up clinics might be a promising source of data. Both clinics have electronic patient records.

The Child and Youth Data Laboratory could be of assistance with accessing and linking databases. It is part of the Alberta Centre for Child, Family and Community Research, a non-profit organization funded by the Alberta Children and Youth

Services. Many Ministries and Departments of the Alberta Government are partners of the Centre, including Children and Youth Services, Education, Health and Wellness. The Laboratory has the mandate to build the research capacity of the Centre for Child, Family and Community Research. Its roles include building the infrastructure that meets the technical and security requirements to support research activities, developing and supporting projects, and performing analyses.

While the Child and Youth Data Laboratory does not at this time hold all the datasets required for ASD surveillance in Alberta, it could provide the required infrastructure for the development of such a program.

Foreseeable opportunities in British Columbia

In British Columbia, services for children with ASD are funded by the Ministry of Children and Family Development. Health services are administered by the Ministry of Health and schools by the Ministry of Education.

The British Columbia Autism Assessment Network (funded by Health), tracks its referrals and assessment in a common database (STAR BC). The data captured describe children not only in terms of their ASD diagnosis, including their Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview (ADI) results, but also in terms of their functional needs and strengths. According to Dr. Stephen Wellington, Medical Director, 75% of the children referred for a diagnostic assessment of ASD come to BCAAN. It excludes children with ASD assessed privately and children from First Nations.

As BCAAN's mandate is restricted to assessment, the use of its database- STAR BC - in ASD surveillance would need to be supplemented with linked data from other Health datasets as well as those from Education and Children and Family Development.

PART 3: Key Findings and Next Steps

The key findings are as follows:

1. The prevalence of ASD in Manitoba estimated using data from NEDSAC is substantially lower than the prevalence estimated using data from the MCHP.
2. A potential data quality issue was identified in relation to updating the status of individuals in NEDSAC under the current protocol.
3. Several potential data quality issues were identified in terms of including individuals in prevalence estimates for the correct study years under the NEDSAC's current protocol.
4. Without further investigation, we cannot determine whether the 299 ICD-9 code has sufficient specificity to allow us to consider evaluating the completeness of NEDSAC's case capture. It is particularly relevant to Ontario where NEDSAC considered using administrative health data from the Institute for Clinical Evaluative Sciences (ICES).
5. Using the MCHP data would expand the list of reportable indicators considerably compared to using NEDSAC alone.
6. There are several potential and known data quality issues related to capturing certain indicators in the MCHP data.
7. There are some indicators currently collected in NEDSAC that are not be available in the MCHP data.
8. Ontario, Québec, Alberta and British Columbia have infrastructures to facilitate data linkage for ASD surveillance using administrative data; however, significant work will be required to develop the required partnerships and data sharing agreements.
9. In Prince Edward Island and Newfoundland and Labrador, there is no need to alter NEDSAC's current data collection (reliance on service provision data) to administrative data linkage.

Recommended next steps are as follow:

1. Develop and validate an algorithm to define ASD case status in Manitoba using administrative data. Test different combinations of ASD coding in the administrative data at MCHP (e.g. one claim in Physician Billing data only, at least one claim in Physician Billing data, at least one claim in Physician Billing data AND at least one claim in Education data, etc.) against a gold standard chart review to determine how best to assign case status using administrative data in Manitoba.
2. Determine whether the date an ASD code first appears in Health, and, if possible, Education data at MCHP accurately reflects the date of diagnosis.
3. Re-evaluate which indicators should be collected as part of an ASD surveillance program using administrative data.
4. Develop a protocol for access to indicators that can be accurately captured in the MCHP datasets and are not captured in NEDSAC.
5. Work with MCHP and Child and Family Services to add inFACT data (including ASD diagnostic information) to the annual data transfer from Family Services and Consumer Affairs to MCHP.
6. Continue to collect information in Manitoba using the current NEDSAC protocol until the above agreement is reached (recommendation #5).

7. Engage in discussions with identified data holders in Ontario, Québec, Alberta and British Columbia to develop partnership for ASD surveillance using administrative data guided by current and future findings in Manitoba (re: recommendations #1, 2 and 3).
8. Continue to collect information in South Eastern Ontario using the current NEDSAC protocol until the above agreement is reached (recommendation #7).
9. Continue to collect information in Prince Edward Island and Newfoundland and Labrador using the current NEDSAC protocols.
10. Work with the Public Health Agency of Canada to complete a capacity review for ASD surveillance using administrative data in the remaining three provinces and three territories.
11. Secure funding to undertake the recommended actions.

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Appendix 1. The Manitoba Centre for Health Policy

The Manitoba Centre for Health Policy (MCHP, www.mchp.ca) is a research unit in the University of Manitoba's faculty of Medicine that conducts population-based research on health services, population and public health, and the social determinants of health. The MCHP develops and maintains a comprehensive population-based data repository on behalf of the Province of Manitoba. The Population Health Research Data Repository is a comprehensive collection of administrative, registry, survey and other databases primarily comprising residents of Manitoba. The MCHP Repository consists of databases received from Manitoba Health, Manitoba grade and high schools and post-secondary colleges, Healthy Child Manitoba and Community and Social Services. MCHP holds databases grouped into the following six domains:

Health: administrative, survey and clinical databases, including visits to physicians, admissions to hospitals and personal care homes, home care use, and pharmaceutical prescriptions dispensed

Education: Manitoba grade school / high school and post-secondary college databases

Social: Healthy Child Manitoba, Community and Social Services, and Survey social data

Justice: Incident Reporting System

Registries: Manitoba Health Insurance Registry, Vital Statistics Mortality, Provider Registry, and Metis Registry

Database Support Files: Population counts for denominators, Drug Identification Number Master file.

Within all available datasets, the following were retained as potentially relevant to ASD surveillance:

- The Hospital abstracts were selected as information on all residents and non-residents of Manitoba is available, in terms of who were hospitalized in acute- and chronic care facilities located in the Province of Manitoba. Of importance to ASD, is that the clinical information in the Hospital Abstracts data covers up to 16 diagnoses and 12 surgical procedures coded according to the ICD-9-CM classification system and up to 25 diagnoses and 20 procedures that are coded according to the ICD-10-CA and the Canadian Classification of Health Interventions (CCI) from April 1, 2004 onward.

- The Medical Services (or Medical claims) data contain records of claims for visits to doctors' offices, admissions to hospitals and personal care homes (PCHs), lab and x-ray procedures performed in doctors' offices and hospitals (including outpatient departments and emergency rooms); and claims for on-call services . The majority of physician claims for children with a diagnosis of ASD are from

physicians practicing in Winnipeg, regardless of where the child resides. The Child Development Clinic in Winnipeg is likely the place where most of these diagnoses are made. This provides a specific resource in ASD surveillance.

- The administrative education databases include data from Manitoba Education (ME). Data-reporting to ME is mandatory and universal for private and public schools, as well as for students who are home schooled. The ME databases contain de-identified records for Manitoba students from Kindergarten (and in some cases Nursery School) through Grade 12

- The Social Assistance Management Information Network is maintained by the Manitoba Department of Family Services and Housing. It contains information on income assistance and the reason for receipt of income assistance (e.g., provided for reasons of mental retardation and multiple handicapped).

Table A1.1. List of data relevant to the surveillance of *ASD* hold by the MCHP.

Database	Years of Data Required	Fields of Interest
Manitoba Health Registry	01/1988 to 12/2007	For each study year and for every instance of a ASD code, we are interested in the: - sex - year of birth (age category) - whether born in Manitoba - health region of residence - year moved out of province or died - year moved to province For the 2007 study year only: - parental Age (at birth of child) - Whether any siblings have a ASD - marital status of parents
Medical Claims (Physician Billings)	01/1988 to 12/2007	For each study year and for every instance of a ASD code, we are interested in the: - specific ASD code, - year it appears - sex - year of birth (age category) - health region of residence -the following diagnostic codes: 237; 290-298; 300-319; 343; 345; 758-759; F00-F83; F85-F99; G40-G41; G80; and Q80-Q99. We are interested in the specific diagnostic codes, and whether these codes appeared only before the ASD code, only on or after the date of the ASD code, or both before and on or after the date of the ASD code. For the 2007 study year only: - Whether any siblings have a ASD diagnosis

Database	Years of Data Required	Fields of Interest
		codes in medical claims - Whether or not mother received prenatal care in relation to the case with ASD - Whether any family member (parents or siblings) has a mental health problem
Department of Education	01/1995 to 12/2007	For each study year and for every instance of a ASD code, we are interested in the: - whether special education funding was received and whether the category of special education funding falls under "autism" or "autism spectrum disorders" - year(s) of funding - sex - year of birth (age category) - region of residence For the 2007 study year dataset: - Level of special education funding - Whether or not attending school - Whether any siblings also have special education funding
Hospital Separations Abstracts	01/1988 to 12/2007	For each study year and for every instance of a ASD code, we are interested in the: - specific ASD code, - sex - year of birth (age category) - health region of residence - the following diagnostic ICD codes: 237; 290-298; 300-319; 343; 345; 758-759; F00-F83; F85-F99; G40-G41; G80; and Q80-Q99. We are interested in the specific diagnostic codes, and whether these codes appeared only before the ASD code, only on or after the date of the ASD code, or both before and on or after the date of the ASD code. For the 2007 study year only: - Whether any siblings have a hospital admission with a ASD diagnosis - Whether any obstetrics complications arose in relation to the case with ASD - Whether any family member (parents or siblings) has a mental health problem
Social Assistance Management Information	01/2007 to 12/2007	For every instance of ASD code: - Whether or not receiving income assistance

Database	Years of Data Required	Fields of Interest
Network SAMIN		
Manitoba Immunization Monitoring System MIMS	01/1993 to 12/2007	For every instance of ASD code: - Whether or not childhood vaccines have been received as per schedule (data requested back to 1993 so immunization schedules for children of varying ages can be determined
Census data	01/2007 to 12/2007	For every instance of ASD code: - Neighbourhood SES
Personal Care Home Database	01/2007 to 12/2007	For every instance of ASD code: - Whether or not lives in personal care home - Whether or not receiving Home Care supports
Home Care Database	01/2007 to 12/2007	For every instance of ASD code: - Neighbourhood SES - Whether or not lives in personal care home - Whether or not receiving Home Care supports

ASD: Autism spectrum disorders

Table A1.2: List of data elements to be extracted for each study year and associated variable(s) of interest

Data Element	Variable of Interest
Sex	Sex
Date of birth	Year of birth, Age category (0-1, 2-4, 5-9, 10-14 years)
Place of birth	Whether born in Manitoba
Address	Health region of residence
ASD diagnosis	For every instance of a ASD code* in the Medical Services, Hospital Discharge Abstracts or Education databases, we are interested in the specific ASD code*, the database in which the code appears, and the year it appears.
ASD diagnosis source	
ASD diagnosis year	
Date moved out of province	Year moved out of province or died
Date of death	
Other diagnoses	We wish to know of every instance where the following diagnostic codes appear for cases in the study datasets: 237; 290-298; 300-319; 343; 345; 758-759; F00-F83; F85-F99; G40-G41; G80; and Q80-Q99. We are interested in the specific diagnostic codes, and whether these codes appeared only before the ASD code, only on or after the date of the ASD code, or both before and on or after the date of the ASD code.
Other diagnoses year	

ASD: Autism spectrum disorders
*299, 299.0, 299.1, 299.8, 299.9, F84.0, F84.1, F84.2, F84.3, F84.4, F84.5, F84.8, F84.9, "ASD"

Table A1.3: List of additional data elements to be extracted for the 2007 study year dataset

	Data Element	Source
About the Child with ASD	Level of special education funding	Education
	Whether or not attending school	Education
	Whether or not receiving income support	SAMIN
	Whether or not childhood vaccines have been received as per schedule	MIMS
	Neighbourhood SES	MB Population Research Registry and Census data
	Whether or not lives in personal care home	Personal Care Home Database
	Whether or not receiving Home Care supports	Home Care Database
	Whether or not lives in a lone parent household	MB Population Research Registry
About family members	Parental Age (at birth of child)	Hospital Discharge Abstracts
	Whether any siblings have a ASD	All; we recognize that this is only available for siblings living in the same household as the child with a ASD
	Whether any obstetrics complications arose in relation to the case with ASD	Hospital Discharge Abstracts
	Whether or not mother received prenatal care in relation to the case with ASD	Medical Services
	Whether any family member (parents or siblings) has a mental health problem	Medical Services, Hospital Discharge Abstracts

Appendix 2. Additional findings

Table A2.1. Characteristics of cases identified in single data source only

	Medical Services Database only	Hospital Discharge Abstracts Database only	Education Database only	NEDSAC only
	2006-2007	**2006-2007**	**2006-2007**	**2006-2007**
Total n	601	14	247	63
Boys, n (%)	425 (70.7)	10 (71.4)	215 (87.0)	49 (77.8)
Year of birth, n (%)				
≤1994	124 (20.6)	s	93 (37.7)	18 (28.6)
1995-1998	186 (31.0)		108 (43.7)	21 (33.3)
1999-2002	179 (29.8)		46 (18.6)	18 (28.6)
2003-2007	112 (18.6)		0 (0.0)	6 (9.5)
Health region of residence*, n (%)				
Winnipeg	411 (68.3)	s	142 (57.5)	36 (57.1)
Central	28 (4.7)		35 (14.2)	5 (7.9)
Interlake/Parkland	50 (8.3)		20 (8.1)	s
North and South Eastman	45 (7.5)		18 (7.3)	6 (9.5)
Assiniboine/Brandon	40 (6.7)		22 (8.9)	11 (17.5)
Burntwood/Churchill/Norman	27 (4.5)		10 (4.0)	s
Unknown	0 (0.0)		0 (0.0)	0 (0.0)
Born in Manitoba†, n (%)	550 (91.5)	12 (85.7)	194 (78.5)	48 (76.2)

NEDSAC: National Epidemiologic Database for the Study of Autism in Canada
s: Data suppressed due to small cell counts.
*Residence for records in NEDSAC is determined by Family Services Regions; the borders of these may not correspond exactly to those for the Health Regions.
† Numbers are based on cases where a birth record could be located in the Hospital Discharge Abstracts Database
‡ 299, 299.0, 299.1, 299.8, 299.9, F84.0, F84.1, F84.2, F84.3, F84.4, F84.5, F84.8, F84.9, "ASD"
§237; 290-298; 300-319; 343; 345; 758-759; F00-F83; F85-F99; G40-G41; G80; Q80-Q99

	Medical Services Database only	Hospital Discharge Abstracts Database only	Education Database only	NEDSAC only
	2006-2007	**2006-2007**	**2006-2007**	**2006-2007**
Total n	601	14	247	63
Year first identified with ASD code‡, n (%) ≤ 1999 2000-2002 2003-2007	 75 (12.5) 110 (18.3) 416 (69.2)	 s	 5 (2.0) 6 (2.4) 236 (95.6)	 ---
Had other diagnostic codes§ at any time prior to date first identified with ASD code‡, but no other diagnostic codes on or after that date, n (%)	116 (19.3)	0 (0.0)	107 (43.3)	---
Had other diagnostic codes§ assigned on or after date first identified with ASD code‡, but no other diagnostic codes assigned before date first identified with ASD code*, n (%)	100 (16.6)	s	18 (7.3)	---
Had other diagnostic codes§ assigned both before and on or after date first identified with ASD code‡, n (%)	251 (41.8)	10 (71.4)	90 (36.4)	---

NEDSAC: National Epidemiologic Database for the Study of Autism in Canada
s: Data suppressed due to small cell counts.
*Residence for records in NEDSAC is determined by Family Services Regions; the borders of these may not correspond exactly to those for the Health Regions.
† Numbers are based on cases where a birth record could be located in the Hospital Discharge Abstracts Database
‡ 299, 299.0, 299.1, 299.8, 299.9, F84.0, F84.1, F84.2, F84.3, F84.4, F84.5, F84.8, F84.9, "ASD"
§237; 290-298; 300-319; 343; 345; 758-759; F00-F83; F85-F99; G40-G41; G80; Q80-Q99

Table A2.2. Characteristics of cases identified in one or more data sources

	Medical Services or Hospital Discharge Abstracts or Education Databases	Medical Services or Hospital Discharge Abstracts or Education or NEDSAC Databases	Education or NEDSAC Databases
	2006-2007	**2006-2007**	**2006-2007**
Total n	1859	1922	1293
Boys, n (%)	1454 (78.2)	1503 (78.2)	1059 (81.9)
Year of birth, n (%)			
≤1994	468 (25.2)	486 (25.3)	354 (27.4)
1995-1998	681 (36.6)	702 (36.6)	505 (39.0)
1999-2002	540 (29.1)	558 (29.0)	372 (28.8)
2003-2007	170 (9.1)	176 (9.1)	62 (4.8)
Health region of residence*, n (%)			
Winnipeg	1202 (64.7)	1202 (62.5)	776 (60.0)
Central	143 (7.7)	142 (7.4)	113 (8.7)
Interlake/Parkland	149 (8.0)	149 (7.8)	94 (7.3)
North or South Eastman	144 (7.7)	144 (7.5)	96 (7.4)
Assiniboine/Brandon	151 (8.1)	150 (7.8)	110 (8.5)
Burntwood /Churchill /Norman	s	68 (3.5)	37 (2.9)
Unknown	s	67 (3.5)	67 (5.2)
Born in Manitoba†, n (%)	1633 (87.8)	1681 (87.5)	1105 (85.5)

NEDSAC: National Epidemiologic Database for the Study of Autism in Canada
s: Data suppressed due to small cell counts.
*Residence for records in NEDSAC is determined by Family Services Regions; the borders of these may not correspond exactly to those for the Health Regions.
† Numbers are based on cases where a birth record could be located in the Hospital Discharge Abstracts Database
‡ 299, 299.0, 299.1, 299.8, 299.9, F84.0, F84.1, F84.2, F84.3, F84.4, F84.5, F84.8, F84.9, "ASD"
§237; 290-298; 300-319; 343; 345; 758-759; F00-F83; F85-F99; G40-G41; G80; Q80-Q99

Table A2.3. Findings for additional data elements for study year 2007

Data Element	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were residents of Manitoba in 2007 (N=1727)				Cases identified via Hospital Abstracts, Medical Services or Education Databases who were continuous residents of Manitoba from birth to 2007 (N=1514)			
Level of special education funding during 2007/08 school year by age in years, n (%)	Levell II	Level III	Special Needs	Not in School	Levell II	Level III	Special Needs	Not in School
0-4	0(0.0)	0(0.0)	12(7.1)	157(92.9)	0(0.0)	0(0.0)	11(6.8)	150(93.2)
5	42(38.5)	25(22.9)	17(15.6)	25(22.9)	33(36.3)	22(24.2)	16(17.6)	20(22.0)
6	58(41.4)	52(37.1)	19(13.6)	11(7.9)	54(41.2)	48(36.6)	19(14.5)	10(7.6)
7-14	592(45.2)	414(31.6)	270(20.6)	33(2.5)	492(43.5)	364(32.2)	250(22.1)	25(2.2)
School attendance in 2007/08 by age in years, n (%)*								
0-4	12 of 169 (7.1)				11 of 161 (6.8)			
5	80 of 109 (73.4)				68 of 91 (74.7)			
6	127 of 140 (90.7)				119 of 131 (90.8)			
7-14	1259 of 1309 (96.2)				1096 of 1131 (96.9)			
Income support[†], n (%)								
during 2007	169 (9.8)				153 (10.1)			
from 1995–2009	381 (22.1)				347 (22.9)			

ASD: Autism spectrum disorders
MCHP: Manitoba Centre for Health Policy
*Total school attendance is slightly different from the numbers shown in the row above.
[†] Income support is defined as having received provincial employment income assistance for at least two months during the period indicated.
[‡] Urban areas in Manitoba included the cities of Winnipeg and Brandon. All other areas were considered rural.
[§] Data only available for births in 2000/01 or later

Data Element	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were residents of Manitoba in 2007 (N=1727)	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were continuous residents of Manitoba from birth to 2007 (N=1514)
Childhood vaccines received as per schedule, n (%)		
2 year:		
Complete	1227 (71.1)	1159 (76.6)
Incomplete	496 (28.7)	355 (23.4)
Missing	4 (0.2)	0 (0.0)
7 year: *(N= 1,024 age 7 or older)*		
Complete	657 (64.2)	619 (70.2)
Incomplete	364 (35.6)	263 (29.8)
Missing	3 (0.3)	0 (0.0)
11 year: *(N= 354 age 11 or older)*		
Complete	167 (47.2)	159 (52.3)
Incomplete	185 (52.3)	145 (47.7)
Missing	2 (0.6)	0 (0.0)

ASD: Autism spectrum disorders
MCHP: Manitoba Centre for Health Policy
*Total school attendance is slightly different from the numbers shown in the row above.
† Income support is defined as having received provincial employment income assistance for at least two months during the period indicated.
‡ Urban areas in Manitoba included the cities of Winnipeg and Brandon. All other areas were considered rural.
§ Data only available for births in 2000/01 or later

Data Element	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were residents of Manitoba in 2007 (N=1727)	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were continuous residents of Manitoba from birth to 2007 (N=1514)
Rural and urban income quintiles[‡], n (%) Lowest Rural Low-Mid Rural Middle Rural Mid-High Rural Highest Rural Lowest Urban Low-Mid Urban Middle Urban Mid-High Urban Highest Urban Missing	78 (4.5) 86 (5.0) 111 (6.4) 136 (7.9) 131 (7.6) 198 (11.5) 202 (11.7) 264 (15.3) 252 (14.6) 243 (14.1) 26 (1.5)	68 (4.5) 77 (5.1) 92 (6.1) 117 (7.7) 114 (7.5) 171 (11.3) 178 (11.8) 220 (14.5) 207 (13.7) 215 (14.2) 55 (3.6)
Lived in personal care home, n (%) No Yes	1727 (100) 0 (0)	1514 (100) 0(0)
Received home care supports at any time from 1990–2008, n (%) No Yes	1701 (98.5) 26 (1.5)	1489 (98.4) 25 (1.6)
Marital status of mother at birth of child, n (%)	716 (51.4)	721 (51.9)

ASD: Autism spectrum disorders
MCHP: Manitoba Centre for Health Policy
*Total school attendance is slightly different from the numbers shown in the row above.
[†] Income support is defined as having received provincial employment income assistance for at least two months during the period indicated.
[‡] Urban areas in Manitoba included the cities of Winnipeg and Brandon. All other areas were considered rural.
[§] Data only available for births in 2000/01 or later

Data Element	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were residents of Manitoba in 2007 (N=1727)	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were continuous residents of Manitoba from birth to 2007 (N=1514)
Married Other	678 (48.6)	669 (48.1)
Mother's age at birth of child in years, n (%) < 20 20-24 25-29 30-34 ≥ 35 Missing	 80 (4.6) 266 (15.4) 437 (25.3) 430 (24.9) 268 (15.5) 246 (14.2)	 78 (5.1) 260 (17.2) 426 (28.1) 415 (27.4) 265 (17.5) 70 (4.6)
Mother received prenatal care[§], n (%) No Yes Missing	 7 (2.1) 331 (97.3) 2 (0.6)	 7 (2.0) 336 (97.4) 2 (0.6)
Obstetrical complications, n (%) Child not born in Manitoba	 209 (12.1)	 ---

ASD: Autism spectrum disorders
MCHP: Manitoba Centre for Health Policy
*Total school attendance is slightly different from the numbers shown in the row above.
[†] Income support is defined as having received provincial employment income assistance for at least two months during the period indicated.
[‡] Urban areas in Manitoba included the cities of Winnipeg and Brandon. All other areas were considered rural.
[§] Data only available for births in 2000/01 or later

Data Element	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were residents of Manitoba in 2007 (N=1727)	Cases identified via Hospital Abstracts, Medical Services or Education Databases who were continuous residents of Manitoba from birth to 2007 (N=1514)
Baby/mother link not established	38 (2.2)	38 (2.5)
No	820 (47.5)	818 (54.0)
Yes	660 (38.2)	658 (43.5)
Mother or sibling has a mental health problem, n (%)	*(N=1394 families)*	*(N=1390 families)*
No	190 (13.6)	187 (13.5)
Yes	1204 (86.4)	1203 (86.5)
Affected siblings, n (%)	*(N=1394 families)*	*(N=1390 families)*
Families with 1child, with ASD	281(20.2)	277 (19.9)
Families with ≥ 2 children, only 1 child with ASD	1015 (72.8)	1015 (73.0)
Families with ≥ 2 children, ≥ 2 children with ASD	98 (7.0)	98 (7.1)

ASD: Autism spectrum disorders
MCHP: Manitoba Centre for Health Policy
*Total school attendance is slightly different from the numbers shown in the row above.
† Income support is defined as having received provincial employment income assistance for at least two months during the period indicated.
‡ Urban areas in Manitoba included the cities of Winnipeg and Brandon. All other areas were considered rural.
§ Data only available for births in 2000/01 or later

Appendix 3. Proceedings

Autism Spectrum Disorders Surveillance in Canada, Workshop, May 9, 2011, Ottawa

Background

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC; www.nedsac.ca) was established in 2001 with funding from the Canadian Institutes of Health Research to monitor autism spectrum disorders (ASD) among Canadian children. As part of NEDSAC commitment to provide effective surveillance of ASD, the improvement of its existing surveillance system is critical. NEDAC is also committed to ongoing relationship building to expand the scope of its surveillance to other provinces in Canada.

The *Autism Spectrum Disorders Surveillance in Canada* workshop held on the 9th of May, 2011 in Ottawa, was organized by NEDSAC (with financial support from the Public Health Agency of Canada). This workshop was attended by 21 participants, representing BC, Alberta, Manitoba, Ontario, Prince Edward Island and Newfoundland & Labrador. The Agenda for the workshop can be found on page 66 and the list of participants on pages 67 and 68.

This workshop facilitated the engagement of experts across Canada with the ability to exchange knowledge of surveillance of ASD in their representative provinces, engage in discussion of the infrastructure support for surveillance of ASD and exchange resources/ protocols on how administrative datasets from various sectors can be used in ASD surveillance.

Opportunities and Challenges

As part of the objectives of the day, the opportunities for and challenges in using administrative datasets for ASD surveillance were noted. Research completed in Manitoba on the use of administrative datasets in ASD surveillance was presented, as well as current NEDSAC protocols to collect data in Prince Edward Island and in Newfoundland & Labrador. Current surveillance strategies and/or the infrastructure in place for potential surveillance were also presented for Alberta, British Columbia, Québec and Ontario.

The participants engaged in discussions and provided information and resources that could be used to enhance surveillance strategies. Several discussion sessions allowed for thorough compilation of opportunities and challenges regarding the use of administrative data for surveillance.

The workshop participants identified three key opportunities or benefits of using administrative data:

1. utilizing existing data reduces cost
2. an administrative data approach can provide the opportunity to combine data from various sources like education, health and social services

3. because administrative datasets are typically owned by provincial government departments, use of such data in national surveillance results in the engagement of important stakeholders (federal and provincial governments).

A number of challenges inherent in using administrative data for surveillance were also identified:

1. administrative data is not designed with surveillance or research in mind
2. finding effective linkages of data between multi-sectors (health, education, social service or community services)
3. privacy, confidentiality concerns
4. approvals to access data
5. sustainability and verification of data
6. ability to control for population change and age
7. data verification
8. inclusion of First Nations communities

Presentation Summaries

Administrative data for ASD Surveillance in Canada – An Opportunity & a Challenge

Hélène Ouellette-Kuntz

The presentation was an overview of the creation of NEDSAC and the last 10 years of contributions to ASD surveillance and establishing relationships with provinces. A grant from CIHR enabled NEDSAC to be established in 2001. The current partnership with the Public Health Agency of Canada under the Enhanced Surveillance of Chronic Diseases Program has supported research to explore administrative data as an improved method of surveillance.

An overview was presented on the use of administrative data, the various challenges and opportunities experienced. NEDSAC receives data for surveillance purposes from Newfoundland & Labrador, Prince Edward Island, Southeastern Ontario and Manitoba. A brief overview of the data collection methods in each was provided.

NEDSAC: Challenges and Opportunities in Three Provinces

1. Newfoundland and Labrador

Paulette Jackman & Paula Hennessey

Newfoundland & Labrador has a large geographical area and a higher rural to urban population. The Department of Education is a great source of information on children with ASD. In 2000, ASD consultants were hired to coordinate the number of children with ASD known to the Department of Education. Challenges exist in tracking the number of children and coordinating data for younger children that are not in the school system, in which case, data from the Department of Health becomes important. Concerns were raised about duplicate and triplicate data entries which resulted in improved data verification methods. No information is collected from private schools.

The Department of Health has 4 regional health authorities that where ASD diagnoses are made. The province provides universal developmental screening for children at two months and 18 months. Delays are found for screening and diagnostic assessments that can take from 3 to 9 months. Efforts are underway to train physicians in the diagnosis of ASD. ASD falls under the pervasive spectrum disorders diagnosis coding and can be difficult to discern from other disorders found under this category from the Health data.

The collaboration of the Department of Health with the Department of Education is vital for effective data collection and continued surveillance efforts.

2. Prince Edward Island

Marlene Breitenbach

In Prince Edward Island, the Department of Education and Department of Social Services and Seniors have merged such that today information of ASD in this province is available from this one source. Data collected since 2008 is provided by an Autism Coordinator through the Department of Education. A large database is in place, and is able to capture the majority of cases of ASD in the province. Challenges were encountered in merging the data from the two departments as privacy concerns had to be addressed.

At present all preschool children are diagnosed by the autism diagnostic team that includes a pediatrician and a psychologist. Wait times are long for diagnosis and this affects access to services and funding. There is an increasing number of children with unmet needs. Throughout the Island various diagnostic practices are in place and a clarification in "golden standard" needs to be addressed to optimize service provision and to unify best practices. No information is available about the First Nations students and no sources of early identification are available for this population.

Some suggestions for future improvements for ASD surveillance in PEI is increasing the frequency of data collection, examining methods for improving data quality, and unifying diagnostic and educational teams for ASD diagnosis and services.

3. Manitoba

Dickie Yu presented by Shahin Shooshtari

In Manitoba, NEDSAC partnered with Children's Special Services, a program of Manitoba Family Services and Consumer Affairs. Children's Special Services provides services and supports to families who may need assistance with caring for a child with disabilities. Once a child is deemed eligible for the program, a Family Services Worker is assigned to the family and works in partnership to develop a Service Plan.

Manitoba has 8 regional centres that coordinate and collect the data for NEDSAC. A case worker in each region completes the NEDSAC Demographic and Diagnostic Information Form. The encrypted database is updated every few months and sent to NEDSAC.

Challenges have presented in the form of privacy and confidentiality agreements to access data, high staff turnover and communication barriers that have resulted in gaps in data. There are concerns of how data is collected by Children's Special Services. Aboriginal children are not captured in the databases. Improving on processes to use medical claims would provide better linkage and case capture for all residents in Manitoba.

Manitoba Centre for Health Policy: an Opportunity

Marni Brownell

The Manitoba Centre for Health Policy is an independent research centre that maintains a population data health repository that includes data from health, education, registries, and social services. MCHP have highest standard of security, privacy and confidentiality overseen ethics review, the health privacy committee and other stakeholders.

Data linkage occurs with appropriate approvals on a project by project basis. Data is available from prenatal to adulthood on everyone that is registered for health care, through hospitalizations, physicians visits, receipts of income assistance, child welfare, residence and family composition. MCHP, by using a Personal Health Identification Number (PHIN) which is unique for each individual, can link data more easily and can create a clearer picture of the development of each individual.

Challenges exist in finding the appropriate linkage to use multiple data sources and privacy approvals. The PHIN is also related to residence and concerns of changing residence would affect surveillance efforts.

Manitoba Centre for Health Policy's ASD Data: Lessons Learned (the Challenges)

Helen Coo

This presentation provided the results of research completed in Manitoba, using administrative data, in partnership with the Manitoba Centre for Health Policy (MCHP). Helen Coo presented the challenges encountered and the future steps needed to address linkage of data, the selection of indicators and the current case ascertainment methods. In preparation of the data set for study, 75% linkage of data was obtained, and the results confirmed that NEDSAC may be missing a substantial number of cases in Manitoba.

Some potential recommendations from this research would be to utilize the Health and Education datasets at the MCHP, as a supplement or replacement, for the current case ascertainment methods used by NEDSAC. Further validation studies of the data are required and understanding the full scope of how well the 299 code identifies ASD cases is essential. In continuing further work with the Manitoba Centre for Health Policy's data , expansion of the list of reportable indicators would need to be considered and the optimal way to capture these indicators.

Explorations in two more provinces: Québec and Ontario

Virginie Cobigo

This was an overview of the potential opportunities for surveillance in Quebec and Ontario. In Quebec multiple sources exist that have potential for ASD surveillance. The *Régie de l'Assurance maladie du Québec* (RAMQ) administers the public health and prescription drug insurance plans. This provides a repository for population-based health information but no structure is in place to support researchers.

The *Ministère de l'Éducation, du Loisir et du Sport* (MELS) collects data for children between the ages from 6 to 16. The *Régie des Rentes du Québec* (RRQ), *Ministère de la Solidarité sociale, Supplément pour enfant handicapé* (Supplement for handicapped children*)* provides financial assistance for parents who have children with a handicap. Information is available on children between the ages of 0 to 18.

The *Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement Système d'information clientèle – Déficience intellectuelle* (SIC-DI) and *Système d'information pour les personnes handicapées* (SIPAD) is also in place. This collects information on those that receive specialized services for all ages. The SICDI has data between the years of 2000 to 2010.

Although all these agencies exist, obtaining approvals to access data is complicated and authorization would need to be asked of many stakeholders. No structure is in place that can facilitate data linkage and access to the data.

In Ontario, the Institute for Clinical Evaluative Sciences (ICES) provides population-based health information. ICES is an independent organization that conducts health services research by utilizing information demographics, health services utilization, and diagnoses. The data available is limited to health, and data from multi sectors are required for ASD. Data sharing agreement would need to be formulated

between ICES and other entities. The process would require 1 to 2 years to complete, and a willing from all stakeholders would be required.

Opportunities in Alberta

Xinjie Cui

The Child and Youth Data Laboratory (CYDL) in Edmonton is a not-for-profit research centre that is funded by the government. This centre supports priority research through research funding and provides knowledge mobilization and builds research capacity through data sources. Information is integrated from government administrative data across nine child serving ministries across the province.

Data Sharing Agreements between ministries and CYDL which fulfill legislative requirements of data use for research purpose are being developed. Legislative requirements those outlined in the Health Information Act (HIA), the Freedom of Information and Privacy Act (FOIP) and Personal Information Protection Act (PIPA). The centre provides the highest security standards and has a "state of the art" Anonymous Identify Resolution System (Crosswalk/AIRS) that enables personal information to be completely anonymous. The linkage of various data is complex but results have been positive.

For ASD surveillance, sectors and organizations that could contribute to data collection are Health and Wellness, Education, Children and Youth Services, Autism Follow-up Clinics, Glenrose Rehabilitation Hospital, Children's Hospital, Community Mental Health services.

At present, the Education data are not reliable for ASD surveillance as coding is not based on clinical diagnoses. Codes reflect the impact of a child's difficulties on his or her learning (mild, moderate, or severe difficulty), and ASD can occur in any of these categories.

It is important to note that Health data cannot be imported out of province.

Opportunities in British Columbia

Steve Wellington and Karen Kalynchuk

The team in British Columbia has created the largest database of children with an ASD in North America which describes children not only in terms of their ASD diagnosis, including their ADOS and ADI results, but also in terms of their functional needs and strengths, which gives flexibility to their data and is useful for research. Their database is also web accessible which allows easier linking and recentralization. In addition, they are working towards a uniform case definition which would give their data longitudinal stability. There is concern that some children, such as those from immigrant families, may be missed.

Challenges associated with collecting data in British Columbia have to do mostly with missing data. The team does not receive any information from the private sector and they must rely on funding agencies to collect data. Also, they have no

access to data from the First Nations. The spread of regional districts also causes some problems when linking data. British Columbia is constantly undergoing review of data quality and has found that 25% of their cases are missing clinical information.

Opportunities with PHAC

Lisa Belzak

Lisa Belzack outlined the Public Health Agency of Canada (PHAC)'s mandate and approach to surveillance noting that the Agency was established to provide oversight and a government structure for public health surveillance. It provides six core functions:

1. public health surveillance,
2. population health assessment,
3. disease and injury prevention,
4. health promotion,
5. health protection, and
6. emergency preparedness and response.

In these core functions PHAC monitors trends in health, detects any emerging issues, provides assessment of the risks, and provides a response in the form of information and tools.

In turns of the national autism strategy, the lead is Health Canada and funding is provided to PHAC to do surveillance and CIHR to coordinate research. Part of the first steps in working towards a national strategy was to perform an environmental scan examining administrative data (which was done with NEDSAC), Registries, Population-based surveys, clinical databases/repositories, NGO and professional networks (CPS, CAPH-C, CASDA, etc.) as well as looking at other successful models.

The next steps would be to formulate an Expert Advisory Committee which would include researchers, practitioners, and other stakeholders and a Scientific Expert Working Group to determine the best strategy and methods for surveillance.

Future considerations

In conclusion, participants of the workshops identified some important solutions and future steps for ASD surveillance and the future of NEDSAC:

1) Raising awareness among various government departments in respective provinces. It was suggested that some provinces would be particularly interested if surveillance activities were broadened to include all developmental disorders, including Fetal-Alcohol Syndrome Disorders (FASD).

2) Surveillance strategies may vary from one province to another as the best way to capture information about affected children may differ.

3) There is so capacity to build synergistic database systems in at least 3 provinces (Alberta, British Columbia, Manitoba).

4) Developing multilateral data sharing agreements between provincial privacy officers will need to be considered.

5) The provision of national standards for case definition will be critical.

6) The Public Health Agency of Canada has a key role to play toward the development of a national system for ASD surveillance.

7) Time should be taken to explore lessons learned and experience of different countries: Australia (registries), UK (surveys), USA (admin data), Denmark, Finland and Sweden.

Agenda

Time	Meeting Agenda	Presenter
7:00-8:00	Breakfast Central Break Area or Meeting room	
8:00	Welcome and Introduction	Helene Ouellette-Kuntz
8:15	Administrative data for ASD Surveillance in Canada – An Opportunity & a Challenge	Helene Ouellette-Kuntz
8:40	NEDSAC: Challenges and Opportunities in three provinces	Paulette Jackman & Paula Hennessey (NFLD & Lab) Marlene Breitenbach (PEI) Shahin Shooshtari (Manitoba)
9:40	Manitoba Center for Health Policy: an Opportunity	Marni Brownell (MCHP)
10:00	coffee/tea break interactive break	
10:15	Manitoba center for health policy: Lessons Learned (the Challenges)	Helen Coo (NEDSAC)
10:35	Explorations in two more provinces: Québec and Ontario	Virginie Cobigo (Queen's University)
11:00	Opportunities in Alberta	Xinjie Cui (Alberta)
11:30	Opportunities in British Columbia	Steve Wellington & Karen Kalynchuk (BC)
12:00	Lunch- Served In Trio Restaurant	
13:15	Review of Challenges and Opportunities	Helene Ouellette-Kuntz
13:45	Opportunities with PHAC	Lisa Belzak
14:00	Administrative Data for ASD Surveillance in Canada – An Opportunity or Too Much of a Challenge?	Virginie Cobigo to facilitate discussion
15:30	Final Wrap up	Hélène Ouellette-Kuntz
	Continue networking	

List of Participants

Name	Position and Affiliations	City, Province
Lisa Belzak	Manager/ Epidemiologist, MHSc., Developmental Disorders Surveillance Unit Health Surveillance and Epidemiology Division, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada	Ottawa, Ontario
Marlene Breitenbach	Special Education Autism Coordinator, Department of Education and Early Childhood Development	Charlottetown, Prince Edward Island
Marni Brownell	Senior Research Scientist Manitoba Centre for Health Policy (MCHP) and Associate Professor, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba	Winnipeg, Manitoba (via Southern Ontario)
Beata Chledowski	Master's in Applied Health Services Research Candidate Atlantic Regional Training Center (ARTC) Health Services Research, University of New Brunswick	Kingston, Ontario
Virginie Cobigo	Postdoctoral fellow, Queen's University	Kingston, Ontario
Helen Coo	Project Coordinator, National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), Queen’s University	Kingston, Ontario
Angela Cornick	Director, ABA Program & Psychological Services, St. Amant Centre, Winnipeg, MB	Winnipeg, Manitoba
Xinjie Cui	Director, Child and Youth Data Laboratory, Alberta Centre for Child, Family and Community Research	Edmonton, Alberta
Deborah Dewey	Director, Behavioural Research Unit, Alberta Children's Hospital and Professor, Departments of Paediatrics & Community Health Sciences, University of Calgary	Calgary, Alberta
Deborah Gorski	NEDSAC Research Assistant , Queen’s University	Kingston, Ontario
Allan Hendrickson-Gracie	CSS Program Specialist, Community Service Delivery	Winnipeg, Manitoba
Paula Hennessey	Director, Early Childhood Learning Division, Department of Education	St. John’s, Newfoundland and Labrador
Jeanette Holden	Professor, Autism Research Program, Depts. Psychiatry and Physiology, Queen's University	Kingston, Ontario
Paulette Jackman	Professional Development Consultant-Autism Division of Student Support Services, Department of Education	St. John’s, Newfoundland and Labrador
Karen	Program Director BC Autism Assessment Network	Vancouver,

Name	Position and Affiliations	City, Province
Kalynchuk		British Columbia
Suzanne Lewis	Clinical Associate Professor, Department of Medical Genetics, University of British Columbia, and Medical Geneticist, Children's & Women's Health Centre of British Columbia	Vancouver, British Columbia
Tara Longpre	MSc (candidate), Epidemiologist, Developmental Disorders Surveillance Unit, Health Surveillance and Epidemiology Division, Centre for Chronic Disease Prevention and Control , Public Health Agency of Canada	Ottawa, Ontario
Michelle Loranger	NEDSAC Research Assistant, Queen's University	Kingston, Ontario
Marianna Ofner	Senior Advisor/Epidemiologist, MSc, PhD (Candidate), Directors Office/ Developmental Disorders Surveillance Unit , Health Surveillance and Epidemiology Division, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada	Toronto, Ontario
Hélène Ouellette-Kuntz	Director, National Epidemiologic Database for the Study of Autism in Canada, Epidemiologist at Ongwanada, and Associate Professor, Department of Community Health & Epidemiology, Queen's University	Kingston, Ontario
Maureen Seguin	Manitoba Family Services and Consumer Affairs, Disability Programs and EIA and Disability Programs	Winnipeg, Manitoba
Shahin Shooshta	Assistant Professor ,Department of Family Social Sciences, Department of Community Health Sciences, University of Manitoba	Winnipeg, Manitoba
Stephen Wellington	Medical Director, B.C. Autism Assessment Network, Developmental Paediatrician, and Clinical Assistant Professor, Division of Developmental Paediatrics, University of British Columbia	Vancouver, British Columbia