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# Estimating Administrative Prevalence of Intellectual Disabilities in Manitoba

Authors

Hélène Ouellette-Kuntz,[1]
Shahin Shooshtari,[2]
Beverley Temple,[3]
Marni Brownell,[4]
Charles Burchill,[4]
C. T. Yu,[5]
Jeanette J. A. Holden,[6]
Brian Hennen[7]

[1] Departments of Community Health & Epidemiology and Psychiatry, Queen's University & Ongwanada Resource Centre, ON

[2] Departments of Family Social Sciences and Community Health Sciences, University of Manitoba & St. Amant Research Centre, MB

[3] Faculty of Nursing, University of Manitoba & St. Amant Research Centre, MB

[4] Department of Community Health Sciences, Manitoba Centre for Health Policy, University of Manitoba, MB

[5] Department of Psychology University of Manitoba & St. Amant Research Centre, Manitoba

[6] Departments of Psychiatry and Physiology, Queen's University, Director of the Cytogenetics and DNA Research Laboratory, Ongwanada, Ontario

[7] Department of Family Medicine, Dalhousie University, Nova Scotia

Correspondence

Shooshta@cc.umanitoba.ca

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## Abstract

*Study Objective: To provide a reliable estimate of administrative prevalence of intellectual disability (ID) in Manitoba.*

*Methods: Unique identifiers were used to link anonymous records for each individual from several provincial administrative databases. Individuals who met at least one of the following criteria were classified as having ID: 1) received income assistance for reasons of mental retardation; 2) received special education funding for mental retardation or multiple handicaps; and 3) had at least one diagnostic code for ID in their medical records.*

*Results: The overall administrative prevalence of ID among Manitobans was estimated at 4.7 per 1,000 population.*

*Conclusions: The use of linked administrative data increased our ability to provide a more reliable estimate of ID prevalence in Manitoba.*

This study was conducted to estimate prevalence of intellectual disabilities (IDs) at the population level in the province of Manitoba in Canada. IDs are conditions originating before the age of 18 that result in significant limitations in intellectual functioning, and conceptual, social and practical adaptive skills (American Association on Intellectual and Developmental Disabilities, 2008). For the purpose of this paper, the term ID is used in place of mental retardation (MR).

Many individuals with ID will need lifelong support from family and organizations in health, education and social services. Prevalence is an epidemiological measure, which refers to the proportion of population who has a particular illness, status or condition at a certain point in time or within a specific time period (Young, 2005). At the population level, reliable estimates of prevalence of IDs are needed to determine the size of this population for planning purposes, decision making, and service provision to meet the needs of this vulnerable population. According to the World Health Organization (WHO), almost 3% of the world population has some form of ID (World Health Organization, 2001). Prevalence of ID has been well-documented in some developed countries such as the U.K., Finland, the Netherlands, Australia, Ireland, Italy and US (e.g., Arvio & Sillanpaa, 2003; Cans et al., 2003; McConkey et al., 2006; Roeleveld et al., 1997; van Shrojenstein Lantman-de Valk et al., 2005; Leonard et al., 2003; Yeargin-Allsop et al., 2003). There are also reported estimates from South Africa and Pakistan (e.g., Durkin, 2002; Bashir et al., 2002; Christianson et al., 2002). The reported estimates, however, vary considerably throughout the world,

between 2 and 85 per 1,000 population. This variation could be explained by differences in prevalence over time, and among populations, or due to differences in definitions, methods of case ascertainment and criteria for case inclusion employed in the studies.

There have been very few studies that examined the prevalence of IDs among Canadians (see Table 1). In 1973, McDonald conducted a survey to identify children with severe mental retardation (IQ below 50) aged about 10 years, living in the province of Quebec between 1966 and 1969 (McDonald, 1973). She gathered information from all possible sources including hospitals, institutions, schools and homes for children with mental retardation. A total of 507 children were identified and examined by the researcher. This led to a prevalence estimate of 3.8 per 1,000 children aged about 10 years old.

Using data from the British Columbia Health Surveillance Registry, the prevalence of mental retardation of all levels among the 15- to 29-year olds in British Columbia was estimated at 7.7 per 1,000 population (Baird & Sadovnick, 1985)

In 1987, McQueen and Spence estimated prevalence of major mental retardation in the Canadian Maritime provinces including New Brunswick, Nova Scotia and Prince Edward Island (McQueen and Spence, 1987). They identified all children who were living in those provinces on the census date of January 1, 1980 who were born between 1969 and 1972 and had an IQ less than 55 or equivalent. They also included children who were classified by a psychologist as having moderate, severe, or profound mental retardation. These children were identified based on the information gathered from school boards, and a number of health and social services agencies as well as institutions. A total of 307 children were identified: 167 in New Brunswick, 118 in Nova Scotia, and 22 in Prince Edward Island. The prevalence was estimated at 3.65 per 1,000 children aged between 7 and 10 years living in the Canadian Maritime region.

In 1988, based on the fragmentary information available on the epidemiology of mental retardation in Canada, a report by the National Health and Welfare concluded a prevalence of at least 8 per thousand population for all levels of disability, with about equal rates of 4 per thousand for mild (IQ = 50-70) and severe (IQ < 50) levels (Health and Welfare Canada, 1988).

In 2001, an agency survey was conducted in Lanark Country of Ontario and estimated the overall "administrative" prevalence of IDs at 6.5 per 1,000 (Ouellette-Kuntz & Paquette, 2001). In this study, the investigators were able to identify each person affected along with details of service requirements and verify the number of people with ID estimated by the MCSS (Ministry of Community and Social Services). This comparison revealed that both approaches led to gaps in estimating the number of people with ID receiving services and supports. When the MCSS and agency survey figures were combined, the "administrative" prevalence in Lanark Country was estimated at between 8 and 9 per 1,000 (Ouellette-Kuntz and Paquette, 2001).

A more recent Canadian study was conducted in the Niagara Region of Ontario. It found an overall ID prevalence of 7.18 per 1,000 (3.64 per 1,000 for severe ID and 3.54 per 1,000 for mild ID) among teenagers in the Niagara region of Ontario (Bradley et al., 2002). While the prevalence estimate for severe ID in this study is consistent with the Canadian review, the prevalence estimate for mild ID is lower compared to the rate found in the previous Canadian studies (Baird & Sadovnick, 1985; McDonald, 1973; McQueen et al., 1987). It is likely that the "true" prevalence of mild ID might be underestimated in this study since the targeted populations were ascertained only by the identification of people with ID by teachers or other service agency personnel, whereas no data were collected for potentially eligible children who were not identified by teachers (Bradley et al., 2002). Focused on the prevalence of ID among adolescents, the Niagara study did not provide information about other age groups.

In summary, there is a lack of Canadian studies on the prevalence of ID and those that do exist have obtained information either through combining the database of departments of social services and education, or identifying affected people in the health services agencies and schools. Both approaches led to gaps in estimating the number of people with ID receiving services and supports. To avoid the problem of under determination of milder cases and inves-

*Table 1. Estimated prevalence of intellectual disabilities/mental retardation in Canada*

| *Study (year)* | *Region* | *Data Source* | *Conditions* | *Age (years)* | *Prevalence (per 1,000)* |
|---|---|---|---|---|---|
| Bradley et al. (2002) | Niagara Region, Ontario | Schools and agencies providing services to persons with mental retardation | MR | 14-20 | 7.18 |
| Ouellette-Kuntz & Paquette (2001) | Lanark County, Ontario | Combined Lanark County agency survey, Ministry of Community and Social Services (MCSS) and Ministry of Education and training (MET) | ID | all ages | 8.0-9.0 |
| Brown et al. (1997) | Ontario | A survey of randomly selected MCSS funded service organizations across Ontario | ID | all ages | 5.6 |
| Nguyen (1996) | Ontario | MCSS and MET | ID | all ages | 5.6 |
| Health & Welfare Canada (1988) | Canada | Fragmentary administrative data available on the epidemiology of mental retardation | MR | all ages | 8.0 |
| McQueen et al. (1987) | New Brunswick, Nova Scotia, and Prince Edward Island | Cross-sectional survey of population | MR IQ<55 | 7-10 | 3.7 |
| Baird & Sadovnik (1985) | British Columbia | British Columbia Health Surveillance Registry | IQ<50 | Birth years: 1952-1966 | 2.3 |
| McDonald (1973) | Quebec | A survey of hospitals, institutions, schools and homes for children with mental retardation | IQ<50 | Birth year: 1958 | 3.8 |

tigate the prevalence of ID at the population-level, multiple sources of linkable data are needed. We had this opportunity in Manitoba through the Manitoba Centre for Health Policy (MCHP) Population Health Research Data Repository, where we can access high quality linkable data from multiple sources for all residents of all ages. To our knowledge, there has not been any study examining the prevalence of ID at the population-level in Manitoba. The main goal of the present study was to estimate prevalence of ID at the population level using a clear definition and reliable criteria for ID.

# Methods

## Region and Population

The Province of Manitoba with a population of 1.17 million, is the 5th largest among all provinces and territories in Canada. Children under the age of 15 make up 19.6% of Manitoba population. Seniors, aged 65 and over, represent 14.1% of the population (Statistics Canada, 2006). Manitoba has a relatively large aboriginal population (12.7%) among whom a much higher rate of disability is reported (e.g., Ng, 1996). The target population of this study consisted of individuals of all ages residing in the Province of Manitoba. We used the December 31, 2000 population count from the Manitoba Population Registry as the denominator for the estimation of prevalence.

## Data Sources

This study involved analysis of cross-sectional and longitudinal data from multiple administrative databases contained in the Manitoba Population Health Research Data Repository (referred to as the Repository hereafter). The Repository is maintained by the Manitoba Centre for Health Policy (MCHP) of the University of Manitoba, and it contains a comprehensive collection of health and non-health administrative databases covering all residents of Manitoba.

The Repository has been used extensively for conducting population-based research to describe and explain profiles of health and illness and patterns of health care utilization. The quality of data in the Repository has been evaluated as high based on the completeness of the data sets and the accuracy of the information recorded (Brownell et al., 2002; Roos & Nicol, 1999; Roos & Shapiro, 1999; Roos et al., 1987; Robinson et al. 1997). In this study, we examined the linked data from several administrative data sets contained in the Repository. Each data set is described below.

***Population-based Registry.*** The registry contains demographic information such as age, sex, and location of residence for all Manitoba residents who are registered with the provincial department of health, Manitoba Health and Healthy Living (MHHL), to receive health care. The data in the registry include information on Aboriginal peoples who live on First Nations reserves and is updated semiannually. Thus, it provides an accurate number of the population of Manitoba to serve as the denominator in prevalence rate calculations.

***Administrative health databases.*** The administrative health databases were originally developed in 1970 by the provincial government to administer the universal medical insurance plan. The databases contain anonymized records for virtually all contacts with the provincial health care system including physicians, hospitals, personal care homes, and home care, as well as pharmaceutical prescriptions. All individuals registered in the provincial health care program are assigned a nine-digit Personal Health Identification Number (PHIN). The MCHP uses the scrambled PHINs, as the consistent non-identifying research number, which permits researchers to link data across data files and track individuals over time while ensuring confidentiality. There is currently more than 30 years of administrative data housed at MCHP, which has been extensively used for the purpose of population-based health services research.

For the purpose of this study we used data from the following two health administrative databases: *Hospital Abstracts database*, which contains information taken from a person's medical chart that is created at the time the person is discharged from hospital. It includes demographic as well as clinical information relating to inpatient and outpatient services received. The inpatient data include records of acute and chronic admissions to hospital, and stays in a hospital bed of at least one night. Outpatient information includes records on day surgery, defined as "diagnostic or surgical services provided in a hospital setting without admission to hospital" (MCHP, 2009). The clinical information in the Hospital Abstracts data covers up to 16 diagnoses and 12 surgical procedures coded according to the International Classification of Diseases: 9th Revision (ICD-9-CM). The abstracts contain information on all residents and non-residents of Manitoba who were hospitalized in acute- and chronic care facilities located in the Province of Manitoba. They also contain information on all Manitobans who were

admitted to out-of-province facilities. To receive funding for their operating budgets, hospitals are required to submit discharge abstracts to MHHL (MCHP, 2009). *Physician Claims database*, which contains information taken from records of patient contacts with physicians. The primary purpose of the Physician Claims database is financial reimbursement to health care providers for services provided. The clinical information on the physician claims includes only one diagnosis coded according to the ICD-9-CM (MCHP, 2009).

***Education enrolment database from Manitoba Education, Citizenship and Youth.*** This database contains information on assessment, evaluation, and enrollment for all students attending school in Manitoba. We used information on special education funds provided for reasons of intellectual disability to identify some of the cases.

***Social Assistance Management Information Network (SAMIN) database*** which is maintained by the Manitoba Department of Family Services and Housing contains information on income assistance and the reasons for receipt of income assistance including intellectual disability and multiple handicap.

## Study Period and Case Definition

We used the unique identifiers (i.e., the non-identifying research number assigned to each Manitoba resident) and linked data from the above databases to identify all persons of any age who were living with an ID in Manitoba during a 5-year period, between April of 1998 and March of 2003. Individuals who met at least one of the following three criteria were classified as ID cases: 1) those who received income assistance for reasons of ID from Manitoba Department of Family Services and Housing; 2) those who received special education funding from Manitoba Department of Education, Citizenship and Youth for reasons of multiple handicaps usually defined as ID plus one or more physical disabilities; and 3) those who had at least one diagnostic code for ID based on the International Classification of Diseases, 9th revision [ICD9-CM] (World Health Organization, 1977) in either physician claims or hospital abstracts data. Within this system, all diseases/conditions are assigned codes and it is the standard system used by physicians and hospitals. The ICD diagnostic codes used in this study to identify cases with ID included: 317 (mild MR), 318 (moderate, severe, and profound MR), 319 (unspecified MR), 760 (Fetal Alcohol Syndrome (FAS)), and 758 and 759 for chromosomal and congenital anomalies associated with MR (the latter two categories included Down syndrome, Patau and Edward syndromes, fragile X syndrome, and Prader-Willi syndrome). Physician claims have only one 3-digit ICD9-CM code for diagnoses. Hospital records have up to 16 fields for diagnoses with each field containing up to 5 ICD9-CM code characters. All 16 fields were searched for ID diagnoses. For the purpose of the analyses presented in this paper, the diagnosis in the first field was considered as the main one.

## Data Analyses

We computed the average five-year prevalence of ID for all ages (1998–2003) and the period prevalence for each of the five years (1998/1999; 1999/2000; 2000/2001; 2001/2002; 2002/2003). The Cochran-Armitage test was used to examine if there was a significant trend in prevalence over time, between 1998/1999 and 2002/2003. The Cochran-Armitage test is one of the common methods to examine linear trends in proportions and frequencies (Armitage, 1955; MCHP, 2009). Condition-specific (e.g., due to Down syndrome) and age-specific prevalence (by age groups: 0–4, 5–9, 10–14, 15–19, 20–24, 25–29, 30–34, 35–44, 45–54, 55–64, and 65+) were also estimated. Programming and data analyses were performed using SAS® software, version 9.1.

This research was approved by the University of Manitoba Health Research Ethics Board, Health Information Privacy Committee (HIPC) of Manitoba Health and Healthy Living, Department of Family Services and Housing (FSH) and Department of Manitoba Education, Citizenship and Youth (MECY).

# Results

We identified a total of 5,384 individuals of all ages who were living with ID in Manitoba between 1998/1999 and 2002/2003. This yielded an overall prevalence of 4.7 per 1,000 population over the five-year period. Of the 5,384 indi-

viduals, 3,096 (i.e., more than half of cases) were children under the age of 20. The highest prevalence estimates were 11.1 per 1,000 and 10.9 per 1,000 found for age groups of 10–14 years and 5–9 years, respectively.

The overall prevalence decreased after age 19 and was lowest among those aged 65 and over. The highest proportion of ID cases were identified based on the Education database (36.3%). The Hospital Abstracts database was the second main source for identifying cases with ID (28.7% of all cases). This database was the most useful source in identifying cases between the ages of 0 and 4 years. Almost a fifth (18.8%) of ID cases were identified based on the physician claims database only. In fact, a higher number of children aged 5-9 years with ID were identified based on physician claims than the hospital data. Overall, the education database was the most helpful source in identifying ID cases between the ages of 5 to 19 (school age). The Social Assistance database identified the fewest cases, a total of 82, and only those aged 20 or older.

Table 3 shows the prevalence estimates by diagnostic groups. The Manitoba prevalence estimates for fragile X syndrome and Prader-Willi syndrome were consistent with values reported in previous studies. However, the prevalence estimates of all the other conditions were lower than values reported in previous research. In our data, mild mental retardation was by far the largest diagnostic group (4.0 per 1000), with unspecified mental retardation (1.7 per 1,000) being the next most common group.

According to Physician Claims and Hospital Abstracts databases, among children 0–4 years of age, the most prevalent diagnosis was that of Down, Patau or Edward syndrome, followed by FAS. Among children between the ages of 5 and 14, the most prevalent diagnosis was that of an unspecified MR. Unspecified MR was also the most common diagnosis among the older age groups. The overall estimated prevalence for FAS was one of the lowest, with notable differences between younger and older age groups (Table 4).

*Table 2. Administrative prevalence of intellectual disability in Manitoba by age group and source of data from 1998/99 through 2002/03*

| | | | | Source of Data [b] | | | |
|---|---|---|---|---|---|---|---|
| *Age Group* | *Total Number in Repository*[a] | *Number of Cases* | *Prevalence per 1,000* | *Hospital Abstracts* | *Physician Claims* | *Education Database* | *Social Assistance* |
| 00–04 | 73,893 | 530 | 7.20 | 403 | 109 | 36 | 0 |
| 05–09 | 83,364 | 910 | 10.90 | 104 | 174 | 805 | 0 |
| 10–14 | 83,989 | 930 | 11.10 | 137 | 91 | 824 | 0 |
| 15–19 | 81,547 | 726 | 8.90 | 172 | 112 | 580 | 0 |
| 20–24 | 76,456 | 343 | 4.50 | 125 | 133 | 174 | 6 |
| 25–34 | 153,425 | 433 | 2.80 | 245 | 221 | 0 | 25 |
| 35–44 | 184,458 | 507 | 2.70 | 291 | 271 | 0 | 25 |
| 45–54 | 157,398 | 420 | 2.70 | 246 | 223 | 0 | 23 |
| 55–64 | 100,548 | 275 | 2.70 | 185 | 132 | 0 | 0 |
| 65+ | 157,203 | 310 | 2.00 | 210 | 142 | 0 | 0 |
| Overall | 1,152,281 | 5,384 | 4.70 | 2,118 | 1,608 | 2,420 | 82 |

[a] *Total numbers of individuals in each age group are based on Manitoba Population in 2000 reported by Manitoba Health and Healthy Living.*

[b] *Due to overlap, the total number of cases across the four individual databases (last four columns) may be larger than the number of cases (third column).*

*Table 3. Prevalence per 1,000 in Manitoba by diagnostic groups*

| | *Manitoba* | *Past Research* |
|---|---|---|
| Overall | 4.7* | 6.0-9.0[a] |
| Mild MR | 4.0 | 5.0-10.0[b] 2.0–85 for all MR[b] |
| Moderate or Profound MR | 0.4 | – |
| Unspecified MR | 1.7 | – |
| Down, Patau & Edward Syndromes | 0.4 | 1 per 800 live births for Down[c]<br>Less than 0.1 for Patau & Eward[d] |
| Fragile X & Prader-Willi Syndromes | 0.2 | 0.25 for Fragile X.[e]<br>Less than 0.006 for Prader-Willi |
| Fetal Alcohol Syndrome | 0.2 | 0.5-2.0[f] |

* *NOTE: Unlike past research, all ages are included in the Manitoba estimate*

[a] *Health and Welfare Canada, 1988; Ouellette-Kuntz & Paquette, 2001; van Schrojenstein Lantman-de Valk et al., 2006; CDC, 1996;*

[b] *McDonald, 1973; McQueen et al., 1987; Baird & Sadovnick, 1985*

[c] *Harper, P. S. (1998).* Practical genetic counselling *(5th ed.) (pp. 56–70). Boston: Butterworth Heinemann, as cited in Health Canada, 2002*

[d] *Archer et al., 2007*

[e] *Turner et al., 1996*

[f] *Thomson et al., 2006*

Figure 1 shows the period prevalence for each of the 5 years for all ages and diagnoses combined. The estimated prevalence was lowest in 1998/1999 at 1.60 per 1,000 (95% CI = 1.52, 1.70) and highest in 2002/2003 at 2.32 per 1,000 (95% CI = 2.23, 2.41). The results of Cochran-Armitage test showed that the increasing trend in prevalence between 1998/1999 and 2002/2003 was significant ($p < 0.001$).

## Discussion

The study presented in this paper was the first attempt in Manitoba to use record linkage techniques to estimate prevalence of intellectual disabilities at the population-level. Although record linkage is a standard practice in estimation of population-based rates of health conditions and illnesses (e.g., Brownell et al., 2008), this technique was not previously used for the estimation of ID prevalence. One of the strengths of our study is the use of unique identifiers for record linkage purposes, which helped us to identify a large number of individuals with ID in Manitoba without counting duplicated cases.

The methodology of this study, which linked multiple sources of data, improved our ability to identify individuals with ID living in the province of Manitoba. For example, more than one third (36.3%) of all the ID cases in our study were identified based on the Education database only (1,954 cases out of 5,384). This is similar to the study from the United States (Yeargin-Allsop et al., 2003), which identified 40% of their ID cases based on data from the department of education in Atlanta, Georgia. The use of the Hospital Abstracts database in our study increased the total number of ID cases by 1,543. The use of Physician Claims added another 1,013 cases.

Using all the available administrative data for Manitobans, we estimated the overall prevalence of ID at 4.7 per 1,000 population. Our estimated prevalence is, however, lower than the reported rates of 6.0–9.0 per 1,000 population from earlier studies conducted in other Canadian provinces or jurisdictions outside Canada (Ouellette-Kuntz & Paquette, 2001; van Schrojenstein Lantman-de Valk, 2005; McConkey et al., 2006; Centre for Disease Control, 1996). The lower prevalence estimate obtained for Manitobans may be due to

*Table 4. Age group-specific estimates of ID prevalence (per 1,000 population) by diagnostic groups, physician claims and hospital data only, Manitoba, 1998/99-2002/03*

| | | Mild MR | | Moderate or Profound MR | | Unspecified MR | | Down, Patau & Edward Syndromes | | Fragile X & Prader Willi | | FAS | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Age Group | N | n | P | n | P | n | P | n | P | n | P | n | P |
| 00-04 | 73,893 | – | – | 5 | 0.1 | 107 | 1.4 | 157 | 2.1 | 101 | 1.4 | 141 | 1.9 |
| 05-09 | 83,364 | 12 | 0.1 | 13 | 0.2 | 167 | 2.0 | 46 | 0.6 | 19 | 0.2 | 27 | 0.3 |
| 10-14 | 83,989 | 31 | 0.4 | 20 | 0.2 | 82 | 1.0 | 37 | 0.4 | 29 | 0.3 | 40 | 0.5 |
| 15-19 | 81,547 | 42 | 0.5 | 23 | 0.3 | 148 | 1.8 | 27 | 0.3 | 21 | 0.3 | 46 | 0.6 |
| 20-24 | 76,456 | 48 | 0.6 | 32 | 0.4 | 152 | 2.0 | 14 | 0.2 | 10 | 0.1 | 17 | 0.2 |
| 25-34 | 153,425 | 63 | 0.4 | 66 | 0.4 | 289 | 1.9 | 39 | 0.3 | 17 | 0.1 | 8 | 0.1 |
| 35-44 | 184,458 | 88 | 0.5 | 108 | 0.6 | 324 | 1.8 | 56 | 0.3 | 15 | 0.1 | | – |
| 45-54 | 157,398 | 69 | 0.4 | 85 | 0.5 | 277 | 1.8 | 45 | 0.3 | | – | | – |
| 55-64 | 100,548 | 37 | 0.4 | 48 | 0.5 | 200 | 2.0 | 36 | 0.4 | | – | | – |
| 65+ | 157,203 | 47 | 0.3 | 48 | 0.3 | 243 | 1.5 | 8 | 0.1 | | – | | – |

*n = number of cases identified*
*P = prevalence in the population (N)*

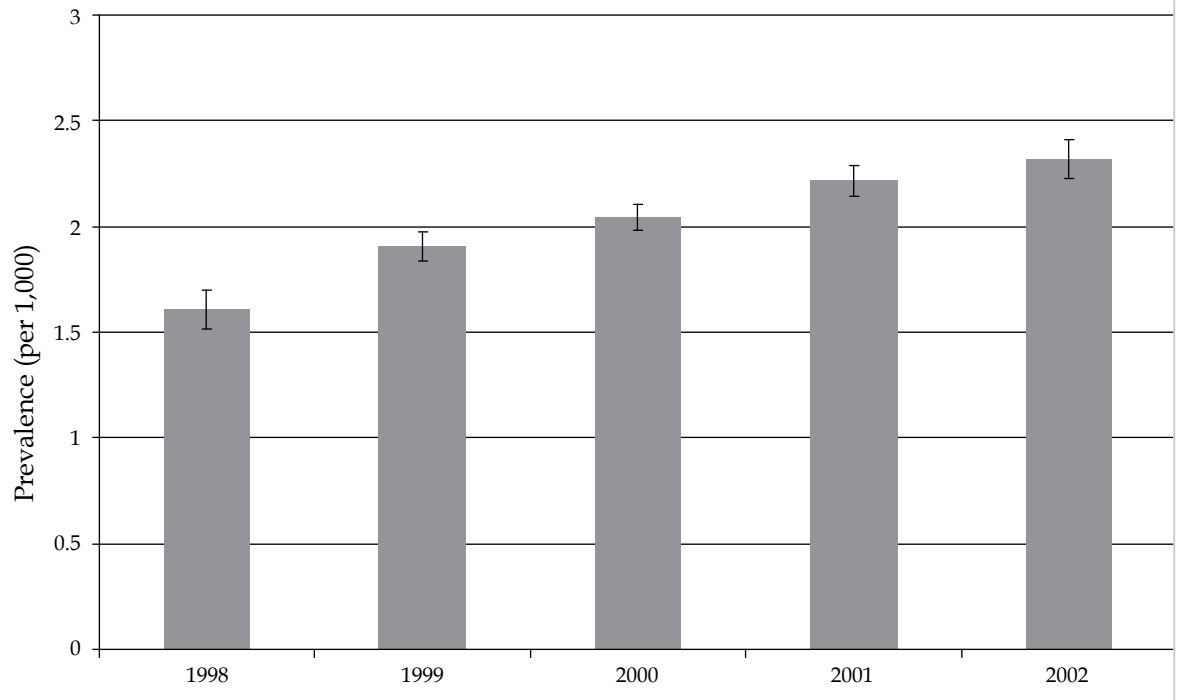


*Figure 1. Administrative prevalence of intellectual disability in Manitoba, All ages, by year, 1998/99–2002/2003*

several reasons. First, it is important to note that our prevalence estimate is based on administrative data and therefore is the "administrative prevalence" of ID conditions. The administrative prevalence is the proportion of the population in a defined area (i.e., the province of Manitoba in this study), who are receiving services or identified to service providers as requiring services. Thus, our prevalence estimates could be in fact an underestimation of true prevalence as relying heavily on the care-seeking behaviour of the individuals themselves or in the case of individuals with ID, their families or support network members. The true prevalence can be obtained by screening population using standard diagnostic criteria and psychometric tests.

Second, in this study we used unique identifiers for record linkage purposes. The use of unique identifiers helped us to more accurately estimate the number of individuals living with ID across the province of Manitoba, without counting duplicated cases, which may have been the case in some of the prior studies, resulting in inflated prevalence rates.

Third, when we look at the prevalence by diagnostic group, our estimated prevalence of FAS, overall, is lower than the expected value from other jurisdictions (e.g., Meaney & Miller, 2003). This underestimate can be explained in part by the fact that more than a 3-digit diagnostic code is needed to identify cases with FAS in the MCHP Data Repository. As explained in the methods section, Physician Claims only have one 3-digit ICD code for diagnosis. This leaves us with only the Hospital Abstracts database as a means for identifying individuals with FAS based on health data. There is also the possibility of underestimation due to variance in accurate use of the diagnostic category or co-morbidity. Several studies report discrepancy in the knowledge of and use of the diagnostic category of FAS (Astley, 2006; Fox & Druschel, 2003; Loock et al., 2005; Meaney & Miller, 2003). For example, children with FAS are more frequently diagnosed with attention deficit-hyperactivity disorder (ADHD) rather than the main disorder of FAS (e.g., Dekker & Koot, 2003; La Malfa et al., 2004). Children who do not display the facial features or have a closer to normal IQ are often misdiagnosed, but their neurological disorders cause problems with life skills (Major Ryan et al., 2006). Previous studies have shown that the rate of FAS is higher in the Aboriginal population than non-Aboriginal populations (Kryskan & Moore, 2005; Szlemko et al., 2006). There is question about the completeness of the provincial administrative databases with regards to the data for Aboriginal populations as provision of health, education and social services falls under provincial/territorial jurisdictions. But, for Aboriginal peoples living on reserve the responsibility falls under federal jurisdictions. While there is question about the completeness of utilization data for Aboriginal Peoples living on reserve, the Population Registry used to extract the total number of population of Manitoba at mid-point in December of 2000 as the denominator for the calculation of prevalence includes Aboriginal peoples living on reserve. This may in fact contributed to the lower prevalence rate estimated.

Finally, unlike other prevalence studies, our estimate includes the entire population. As such, it includes the very young and the very old. As shown in Table 2, the rates decline in adulthood and are also lower among preschoolers. The rates for children 5 to 19 years of age are consistent with other reports. The differences in the prevalence from young children to adolescents could be in part due to developmental trajectories. As the child ages, there are greater demands in adaptive functioning, which may make the impairments more noticeable, leading to a diagnosis of ID.

Our data show an increase in the overall prevalence of ID over time, between the years 1998/1999 and 2002/2003, although its causes are unknown. As with most studies based on administrative prevalence, increase may be due to factors such as increase in incidence, improved diagnostic services, and changing diagnostic criteria. The latter is especially true for FAS, which is a relatively new diagnosis, first described as a birth defect in 1973. Thus, individuals with FAS in the older age groups were not identified in childhood, which explains why no one 35 years and over was identified in our study cohort. None of the previous Canadian studies have examined trends in prevalence over time due to the cross-sectional nature of their data (McDonald, 1973; Baird & Sadovnick, 1985; McQueen & Spence, 1987; Health and Welfare Canada, 1988; Ouellette-Kuntz & Paquette, 2001). More recently, the term Fetal Alcohol Spectrum Disorder (FASD) was introduced, which includes FAS along with Fetal Alcohol Effects (FAE) (e.g., Chudley et al., 2005).

In conclusion, the use of linked data from multiple databases which exist in the Population Health Research Data Repository at MCHP increased our ability to provide a more reliable estimate of the prevalence of intellectual disabilities in Manitoba. The prevalence estimates provided for different age groups and for different diagnostic categories of IDs provide a basis upon which policy development and planning by many governmental departments such as health, education and family services as well as non-governmental agencies providing care and services to individuals with ID and their families in Manitoba can be undertaken. More information however is needed about the individual needs and resources of persons with ID and their families, and the community where they live for more informative planning and provision of services. This type of information is currently lacking in the existing administrative databases in the MCHP Data Repository. The attainment of the full picture requires substantial data enhancements.

Furthermore, as discussed our estimated prevalence rates must be viewed as underestimates and used with caution as there are limitations to our ID case definition as well as the data sources used. Practitioners know there remain in the community individuals with ID who have never applied for social supports, have never attended public schools, and are not diagnosed as having ID in the course of receiving health services. In particular, many high functioning adults get lost in the support systems, in part because they are not eligible or their caregivers deem them not eligible to receive previously provided services. Also some have family and community support that does not depend on government service supplements.

In spite of these limitations, however, with the establishment of our administrative case definition of ID, we are now in a better position to move forward and examine a number of other important health-related issues including trajectories in health and access to health care and social services for this vulnerable population in Manitoba. Such analyses can be enhanced by the inclusion of socioeconomic variables available through Statistics Canada for a given area including population density, urban/ rural setting and income level.

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## References

American Association on Intellectual and Developmental Disabilities (2009). Retrieved January 24, 2009, from http://www.aamr.org/.

Archer, P.A., Langlois, H.P., Suarez, L., Brender J., & Shanmugam, R. (2007). Association of prenatal age with prevalence of selected birth defects. Birth Defects Research (Part A): *Clinical and Molecular Teratology, 79*, 27–34.

Armitage, P. (1955). Tests for linear trends in proportions and frequencies. *Biometrics, 11*, 375–386.

Arvio, M., & Sillanpaa, M. (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. *Journal of Intellectual Disability Research, 47*, 108–112.

Astley, S. J. (2006). Comparison of the 4-digit diagnostic code and the Hoyme diagnostic guidelines for fetal alcohol spectrum disorders. *Pediatrics, 118*, 1532–1545.

Baird, P. A., & Sadovnick, A. D. (1985). Mental retardation in over half-a-million consecutive livebirths: An epidemiological study. *American Journal of Mental Deficiencies, 89*, 323–330.

Bashir, A., Yaqoob, M., Ferngren, H., Gustavson, K. H., Rydelius, P. A., Ansari, T. et al. (2002). Prevalence and associated impairments of mild mental retardation in six- to ten-year old children in Pakistan: a prospective study. *Acta Paediatrica, 91*, 833–837.

Bradley, E. A., Thompson, A., & Bryson, S. E. (2002). Mental retardation in teenagers: prevalence data from the Niagara region, Ontario. *Canadian Journal of Psychiatry, 47*, 652–659.

Brownell, M., Martens, M., & Kozyrskyi, A. (2002). Improving children's health. Using a population-based health information system to study child health. The Manitoba experience. *Canadian Journal of Public Health, 93*(2), (suppl), S9-S14.

Brownell, M., De Coster, C., Penfold, R., Derksen. S., Au, W., Schultz, J., & Dahl, M. (2008). Manitoba Child Health Atlas Update. Winnipeg, MB: Manitoba Centre for Health Policy.

Cans, C., Guillem, P., Fauconnier, J., Rambaud, P., & Jouk, P. S. (2003). Disabilities and trends over time in a French county, 1980–91. *Archives of Disease in Childhood, 88*, 114–117.

Centers for Disease Control and Prevention (1996). State-specific rates of mental retardation – United States, 1993. *MMWR Morbidity and Mortality Weekly Report, 45*, 61–65.

Christianson, A. L., Zwane, M. E., Manga, P., Rosen, E., Venter, A., Downs, D. et al. (2002). Children with intellectual disability in rural South Africa: Prevalence and associated disability. *Journal of Intellectual Disability Research, 46*, 179–186.

Chudley, A.E., Conry, J., Cook, J.L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*, S1-S21.

Dekker, M. C., & Koot, H. M. (2003). DSM-IV disorders in children with borderline to moderate intellectual disability. I: prevalence and impact. *Journal of American Academy of Child and Adolescent Psychiatry, 42*, 915–922.

Durkin, M. (2002). The epidemiology of developmental disabilities in low-income countries. *Mental Retardation and Developmental Disability Research Reviews, 8*, 206–211.

Fox, D. J., & Druschel, C. M. (2003). Estimating prevalence of fetal alcohol syndrome (FAS): Effectiveness of a passive birth defects registry system. Birth Defects Research. Part A *Clinical and Molecular Teratology, 67*, 604–608.

Health and Welfare Canada (1988). The epidemiology of mental retardation. Report of the working group. Ottawa: Author.

Health Canada (2002). Congenital anomalies in Canada – A perinatal health report. Ottawa: Minister of Public Works and Government Services Canada.

Kyskan, C. E., & Moore, T. (2005). Global Perspectives on Fetal Alcohol Syndrome: Assessing practices, policies, and campaigns in four English-speaking countries. *Canadian Psychology, 46*, 153–165.

La Malfa G., Lassi, S., Bertelli, M., Salvini, R., & Placidi, G. F. (2004). Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research, 48*, 262–267.

Leonard, H., Petterson, B., Bower, C., & Sanders, R. (2003). Prevalence of intellectual disability in Western Australia. *Paediatric and Perinatal Epidemiology, 17*, 58–67.

Loock, C., Conry, J., Cook, J. L., Chudley, A. E., & Rosales, T. (2005). Identifying fetal alcohol spectrum disorder in primary care. *Canadian Medical Association Journal, 172*, 628–630.

Major Ryan, J., Bonnett, D., &. Gass, C. (2006). Sobering thoughts: Town hall meetings on Fetal Alcohol Spectrum Disorders. *American Journal of Public Health, 96*, 2098–2101.

Manitoba Centre for Health Policy. (2009). *Population Health Research Data Repository.* Retrieved January 12, 2009, from http://umanitoba.ca/faculties/medicine/units/mchp/resources/repository/index.html

McConkey, R., Mulvany, F., & Barron, S. (2006). Adult persons with intellectual disabilities on the island of Ireland. *Journal of Intellectual Disability Research, 50*, 227–236.

McDonald, A. (1973). Severely retarded children in Quebec: Prevalence, causes, and care. *American Journal of Mental Deficiency, 78*, 205–215.

McQueen, P. C., Spence, M. W., Garner, J. B., Pereira, L. H., & Winsor, E. J. (1987). Prevalence of major mental retardation and associated disabilities in the Canadian Maritime Provinces. *American Journal of Mental Deficiency, 91*, 460–466.

Meaney, F. J., & Miller, L. A. (2003). A comparison of fetal alcohol syndrome surveillance network and birth defects surveillance methodology in determining prevalence rates of fetal alcohol syndrome. Birth Defects Research. Part A *Clinical and Molecular Teratology, 67*, 819–822.

Ng, E. (1996). Disability among Canada's Aboriginal Peoples in 1991. Health Reports, Summer 1996, Vol. 8, No. 1.

Nuyen, M. (1996). What is the prevalence of Ontarians labeled as having a "developmental disability"? Toronto, ON: Developmental Services Branch, Ministry of Community and Social Services.

Ouellette-Kuntz, H., & Paquette, D. (2001). The prevalence of developmental disabilities in Lanark County, Ontario. *Journal on Developmental Disabilities, 8*, 1–16.

Robinson, J. R., & Tataryn, D. J. (1997). Reliability of the Manitoba mental health management information system for research. *Canadian Journal of Psychiatry, 42*(7), 744–749.

Roelevald, N. Zielhuis, G., & Gabreals, F. (1997). The prevalence of mental retardation: A critical review of recent literature. *Developmental Medicine and Child Neurology, 39*, 125–132.

Roos, L. L., & Nicol, P. J., & Cageorge, S. (1987). Using administrative data for longitudinal research: Comparisons with primary data collection. *Journal of Chronic Disease, 40*, 41–49.

Roos, L. L., & Nicol, P. J. (1999). A research registry: Uses, development, and accuracy. *Journal of Clinical Epidemiology, 52*, 39–47.

Roos, N. P., & Shapiro, E. (1999). Academics at the policy interface: Revisiting the Manitoba Centre for Health Policy and Evaluation and its population-based health information system. *Medical Care, 37*(6) (suppl), JS10-JS14.

Statistics Canada (2006). 2006 Census: Portrait of the Canadian population in 2006, by age and sex, Catalogue No. 97-551-XWE.

Szlemko, W. J., Wood, J. W., & Thurman, P. J. (2006). Native Americans and alcohol: past, present, and future. *Journal of General Psychology, 133*, 435–451.

Thomson, A. K., Glasson, E. J., & Bittles, A. H. (2006). A long-term population-based clinical and morbidity review of Prader-Willi syndrome in Western Australia. *Journal of Intellectual Disability Research, 50*, 69–78.

Turner, G., Webb, T., Wake, S., & Robinson, H. (1996). Prevalence of fragile X syndrome. *American Journal of Medical Genetics, 64*, 196–197.

van Schrojenstein Lantman-de Valk H.M., Wullink, M., van den Akker. M., van Heurn-Nijsten, E. W., Metsemakers, J. F., & Dinant, G. J. (2005). The prevalence of intellectual disability in Limburg, the Netherlands. *Journal of Intellectual Disability Research, 50*, 61–68.

World Health Organization (1977). International Classification of Diseases. Manual of the International Statistical Classification of disease, injuries, and causes of death. 9th revision. Geneva, Switzerland: World Health Organization.

World Health Organization (2001). International classification of functioning disability and health. Geneva: Author.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association, 289*, 49–55.

Young, T.K. (2005). Population Health: Concepts and Methods (2nd ed.). Oxford: Oxford University Press.