

Estimating the Prevalence of Children Who Have a Developmental Disability and Live in the Province of British Columbia

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Abstract

Administrative health data for 1986 to 2013 was used to identify the prevalence of childhood developmental disability in British Columbia. A total of 26,320 children who have a developmental disability were found in the data set. Prevalence increased for all categories of developmental disability over the 27-year period. Following 2010, the rate of increase in prevalence for all categories of developmental disability slowed. The increase in prevalence was greatest for autism spectrum disorder. Prevalence data is important to have for planning programs and services for people who have a developmental disability.

This study was conducted to estimate the prevalence of children who have a developmental disability in the province of British Columbia. Information on the prevalence of developmental disability is important for planning long-term policies and services. In addition, statistics are critical in monitoring the well-being of people with disabilities. As Recommendation 9 of the World Health Organization/The World Bank World Report on Disability states: "Research is essential for increasing public understanding about disability issues, informing disability policy and programmes, and efficiently allocating resources" (*World Report on Disability*, 2011, p. 267).

However, there is little information available on the prevalence of developmental disability in Canada or internationally (Fujiura, Rutkowski-Kmitta, & Owen, 2010). Moreover, using the data that do exist is hampered by the differing definitions and terms used to describe developmental disability. Terms such as intellectual disability, developmental disability, mental retardation and neurodevelopmental disability are all used in the literature and may be poorly defined. Despite these drawbacks, some prevalence data are available, providing a rough sketch of this neglected area.

In a meta-analysis of 52 population-based studies from 27 countries, Maulik, Mascarenhas, Mathers, Dua, and Saxena (2011) found that the highest prevalence of developmental disability occurred in low income countries and in child/adolescent age groups. The overall prevalence for high-in-

come countries was 0.92%, the overall prevalence for the child/adolescent population across the 52 studies was 1.83%.

Hogan, Msall, and Drew (2006) reported an overall prevalence of developmental disability in the United States of 13.9 per 1,000 in children aged 5–17 years. In Metropolitan Atlanta, Van Naarden Braun et al. (2015) found that the prevalence of eight year old children with an intellectual disability in 2010 was 13.0 per 1,000 and the prevalence of eight year old children with autism in 2010 was 15.5 per 1,000. Maenner et al. (2016) used the U.S. National Survey of Children's Health (NSCH) and the National Health Interview Survey (NHIS) to determine the prevalence of intellectual disability among children. They found that prevalence varied from 5.7 per 1,000 (NHIS) and 5.9 per 1,000 (NSCH) for 2- to 5-year-olds to 15.0 per 1,000 (NSCH) and 15.9 per 1,000 (NHIS) for 14- to 17-year-olds.

There is evidence that the number of children diagnosed with a disability and particularly with a developmental disability is increasing in developed countries (de Graaf et al., 2011; Halfon, Houtrow, Larson, & Newacheck, 2012; Houtrow, Larson, Olson, Newacheck, & Halfon, 2014; Reichman, Corman, & Noonan, 2008; Shin et al., 2009). Houtrow et al. (2014) analyzed the U.S. National Health Interview Survey datasets from 2001 to 2011. They found that overall the prevalence of childhood disability increased by 15.6% between 2001 and 2011. However, in the same ten year period, they also found that the percentage of disability cases due to a physical health condition declined by 11.8% while the percentage of cases due to neurodevelopmental or mental health conditions increased by 20.9%.

In Canada, there is very little information on the prevalence of developmental disability. Over the five year period of 1998 to 2003, Ouellette-Kuntz et al. (2009) estimated a prevalence of intellectual disability in Manitoba of 4.7 per 1,000 population. They found a prevalence of 11.1 per 1,000 for children aged 10–14 years and 10.9 per 1,000 for children aged 5–9 years old. Bradley, Thompson, and Bryson (2002) found a 7.18 per 1,000 prevalence of mental retardation among teenagers living in the Niagara region of Ontario. In 2009/10, administrative data from Ontario were used to obtain

an estimate of 0.78% of the population as adults with a developmental disability (Lunsky, Klein-Geltink, & Yates, 2013).

The prevalence of children with a developmental disability in British Columbia is unknown. Crude estimates of the number of people with a developmental disability in British Columbia can be assumed from service information from both the B.C. Ministry of Education (for children) and Community Living B.C. (for adults). B.C. Ministry of Education data for 2005/2006 indicate that there were 2,457 students with a moderate to severe/profound intellectual disability; 2,593 students with autism; 2,751 students with a mild intellectual disability; and 16,702 students with a learning disability enrolled in public schools (B.C. Ministry of Education, 2006). This is a total of 24,504 students (4.3% of the total number of students) with some level of learning difficulties enrolled in public schools in 2005/2006 in British Columbia. This does not include students enrolled in private schools, home-schooled or in the public system but without an assessment or identification and therefore likely underestimates the total number of school-aged children who have a developmental disability.

In British Columbia, Community Living B.C. currently provides services to over 20,000 adults with a developmental disability (Community Living B.C., n.d.). This number represents approximately 0.53% of the adult population of British Columbia in 2016. However, Community Living B.C. most likely does not provide services to all adults who have a developmental disability in British Columbia, so this estimate is also likely an underestimate of the actual prevalence.

One under-used tool for obtaining estimates of prevalence is administrative health databases (Lin et al., 2013; Lin et al., 2014). Administrative data have some unique advantages. The most significant advantage is the size of the data set (Jutte, Roos, & Brownell, 2011). The availability and large size of the data sets makes the use of administrative data very cost effective; improves the generalizability of the findings; reduces problems associated with selection bias (Jutte et al., 2011); and provides the ability to select varying comparison groups (Glasson & Hussain, 2008).

This study used health administrative data from the province of British Columbia to estimate the prevalence of children with developmental disabilities. This information will be useful for future planning of programs and services within British Columbia, and may serve as an estimate for other provinces and territories within Canada.

Materials and Methods

As part of a larger population level study of the health of parents and siblings of children with developmental disabilities, data were collected on the prevalence of children who have a developmental disability in British Columbia. Data were obtained from Population Data B.C. (Population Data B.C., 2018).

For this study three data bases were linked. Linkages were done by Population Data B.C. staff and provided to the researchers as data extracts developed in accordance with the request of the researchers and the agreement of the B.C. Ministry of Health and Population Data B.C. ("Data Linkage," 2013) The researchers were allowed access to the data extracts only via the Population Data B.C. Secure Research Environment. The data extracts cannot be removed from that environment and are only available to researchers for a time limited period (Pencarrick-Hertzman, Meagher, & McGrail, 2013). The linked data files for this study were:

1. A central consolidation file providing demographic information on all individuals in British Columbia. The file contains information on birth dates and sex of each individual in the study as well as neighbourhood income deciles and quintiles. ("British Columbia Ministry of Health, (1986–2014): Consolidation File (MSP Registration and Premium Billing). Population Data B.C. Data Extract. B.C. Ministry of Health," 2016).
2. The Medical Services Plan (MSP) payment file that contains administrative information for all fee-for-service care provided by physicians in British Columbia. The file includes the date of each visit to a physician, the diagnostic code (ICD-9), the Health Authority and Health Service Delivery Areas where the visit occurred, and the subsidy code indicating whether payments to the physician were subsidized through provincial programs and the amount of the subsidy ("British Columbia Ministry of Health, (1985–2014): Medical Services Plan (MSP). Population Data B.C. Data Extract. B.C. Ministry of Health," 2016).
3. The hospital separation file with information on all hospitalizations, including the date of admission and discharge and the diagnostic codes (ICD-9 and ICD-10) ("British Columbia Ministry of Health, (1985–2014): Discharge Abstract Database (Hospital Separations). Population Data B.C. Data Extract. B.C. Ministry of Health," 2016).

Data were linked using unique and study specific codes that allow people to be anonymously identified across databases. The B.C. Ministry of Health approved access to and use of the data through Population Data B.C. Ethics approval was granted by the University of Victoria Human Research Ethics Board.

The resulting data extracts provided information on number of people in British Columbia aged 0–19 years old at any time between 1985 and 2014 who had received a diagnosis of a developmental disability. This diagnosis was either a primary diagnosis when these children used medical services or a secondary diagnosis (i.e., a child could be visiting a doctor for treatment for a common childhood illness and the doctor also noted developmental disability as a secondary diagnosis).

Identification of children with a developmental disability used the algorithm developed by Lin et al. (2013). Children aged 0–19 were identified by ICD-9 codes in MSP files and ICD-10 codes in hospital separation files. Identification required at least two occurrences of the ICD-9 codes identifying developmental disability in MSP data, or at least one occurrence of developmental disability identified by ICD-9 or ICD-10 codes in hospital separation data between 1985 and 2014. Data were collected according to ICD-9 and ICD-10 codes on a range of developmental disabilities including fetal alcohol syndrome (FAS), autism spectrum disorder (ASD), Down syndrome and rarer chromosomal abnormalities. This paper used the term fetal alcohol syndrome rather than fetal alcohol spectrum disorder because the ICD-9 and ICD-10 codes are for

fetal alcohol syndrome. There are no codes for fetal alcohol spectrum disorder.

For this study, prevalence was operationalized as proportion of children (defined as aged 0-19) with a developmental disability in British Columbia in each year of the data for the years 1986 to 2013. Thus, a person could have been born in 1970, but would still be a child in the years 1986, 1987, 1988 and 1989. Prevalence information for 1985 and 2014 was omitted due to the fact that data was only available for a portion of each of those two years.

Data from the data extract were also examined for sex of the child, income quintile at birth, and health authority at birth. For descriptive statistics, children with a developmental disability were compared to a cohort of children born between 1990 and 1995 who did not have a developmental disability.

Results

A total of 26,320 children who have a developmental disability were found in the data set. Developmental disabilities were categorized into types (Table 1) according to the ICD-9 and ICD-10 codes used.

Following the initial identification of a developmental disability diagnosis, individuals were

grouped according to a single diagnosis. For example, individuals with a dual diagnosis of Down syndrome and ASD were categorized with Down syndrome and removed from the ASD group, and individuals categorized as Down syndrome and mild mental retardation were categorized with Down syndrome and removed from the Mild group. The following four broad diagnostic groups were formed: autism spectrum disorder (ASD), fetal alcohol syndrome (FAS), Down syndrome and other developmental disabilities (Table 2, following page).

Over half of children with a developmental disability were diagnosed with autism spectrum disorder (58.19%).

Following sorting into diagnostic groups, the data were further analyzed to obtain information on the prevalence of each category of developmental disability for the years 1986-2013 (Table 3, page 51). Prevalence of children with a developmental disability was calculated as a percent of the total number of children in British Columbia ("Provinces age sex population totals," n.d.).

In 2013 the prevalence of children with a developmental disability in British Columbia was estimated at 2.42% of the total population of children in British Columbia. This number is greater than prevalence estimates reported previously in the literature for either the United

Table 1. Total Number of Children With a Particular Developmental Disability Diagnosis 1985-2014

<i>Type of Developmental Disability</i>	<i>Total Number</i>
Autism Spectrum Disorder	15,533
Down Syndrome	2,370
Dual Diagnosis of Down Syndrome and Autism Spectrum Disorder	218
Dual Diagnosis of Down Syndrome and Fetal Alcohol Syndrome	7
Mild Mental Retardation	3,511
Moderate Mental Retardation	869
Severe Mental Retardation	884
Profound Mental Retardation	311
Unspecified Mental Retardation	4,381
Chromosomal Abnormalities (excluding Down syndrome)	1,880
Fetal Alcohol Spectrum Disorder	1,844

Table 2. Grouped Categories and Numbers of Children Who Have a Developmental Disability in British Columbia 1985–2014

Category of Developmental Disability	Number of Children Identified
Autism Spectrum Disorder	15,315
Down Syndrome	2,370
Fetal Alcohol Syndrome	1,837
Other Developmental Disabilities (including chromosomal abnormalities but excluding Down syndrome)	6,798

States or Canada. Similar to studies from the United States, prevalence of the total number of children with a developmental disability in British Columbia increased over time. The increase was from 0.44% in 1986 to 2.42% of the total number of children in British Columbia in 2013. The range of percent increase each year for children with a developmental disability was 0.01–0.10. The smallest increases occurred in the years 2010–2013, indicating a recent slowing in the increase in the number of children with a developmental disability in British Columbia.

Prevalence of each of the four categories of developmental disability also increased with time. The largest increase was for children with ASD. The prevalence of children with ASD increased from 0.14% in 1986 to 1.49% in 2013. The smallest increase over time was for children with Down syndrome.

Table 4 (see page 53) shows information regarding some descriptive statistics for each of the four categories of children with a developmental disability compared to children born in 1990–1995 who did not have a developmental disability. Significant differences occurred in the number of males and females between the four disability groups and the group without developmental disabilities. Each of the disability groups had higher numbers of males. The difference was particularly great for individuals with ASD (78% of children with ASD were male).

Using the year of birth (not the year of diagnosis), additional comparisons were made between the children with a developmental disability and the children without a developmental disability regarding income and location within

British Columbia (Health Authority) at birth. Income and Health Authority data were not available for all of the children with a developmental disability, indicating that either the children were not born in British Columbia or data was missing for some other reasons. Data were available for 72% (income quintile at birth) and 74% (Health Authority at birth) of children with ASD, 65% (income quintile at birth) and 68% (Health Authority) of children with Down syndrome, 63% (income quintile at birth) and 69% (Health Authority) of children with FAS and 49% (income quintile at birth) and 53% (Health Authority) of children within the Other category.

Significant differences were found in income quintiles at birth between the disability groups and the comparison group. This difference was particularly large for individuals with FAS (45% of children with FAS were in the lowest income quintile at birth).

There were also significant differences in place of birth between the groups, again, particularly evident for individuals with FAS. Thirty-three percent of children with FAS were born in the Northern Health Authority, while only approximately 6.3% of the provincial population lives in that geographic region (“Northern Health,” n.d.). When Health Service Delivery Areas (HSDAs) were examined, it was found that 26% of children with FAS were born in the Northern Interior HSDA.

Discussion

Based upon population level administrative data, this study provided information on the prevalence of children who have a develop-

Table 3. Prevalence of Children (aged 0–19) With a Developmental Disability in British Columbia 1986–2013

Year	Autism Spectrum Disorder (percent of total children in B.C.)	Down Syndrome (percent of total children in B.C.)	Fetal Alcohol Syndrome (percent of total children in B.C.)	Other Developmental Disability (percent of total children in B.C.)	Total Number of Children with a DD (percent of total children in B.C.)	Total Number of Children in B.C.	Absolute Percent Increase in Children With a DD (year over year)
1986	1,139 (0.14)	512 (0.06)	104 (0.01)	1,884 (0.23)	3,639 (0.44)	823,031	
1987	1,348 (0.16)	561 (0.07)	132 (0.02)	2,075 (0.25)	4,116 (0.50)	828,773	0.06
1988	1,606 (0.19)	608 (0.07)	170 (0.02)	2,266 (0.27)	4,650 (0.55)	842,206	0.05
1989	1,879 (0.22)	655 (0.08)	225 (0.03)	2,468 (0.29)	5,227 (0.61)	858,240	0.06
1990	2,247 (0.26)	715 (0.08)	285 (0.03)	2,693 (0.31)	5,940 (0.68)	878,769	0.07
1991	2,638 (0.30)	801 (0.09)	345 (0.04)	2,903 (0.33)	6,687 (0.75)	892,328	0.07
1992	3,084 (0.34)	847 (0.09)	425 (0.05)	3,099 (0.34)	7,455 (0.81)	915,654	0.06
1993	3,577 (0.38)	903 (0.10)	502 (0.05)	3,346 (0.36)	8,328 (0.89)	938,321	0.07
1994	4,162 (0.43)	972 (0.10)	583 (0.06)	3,595 (0.37)	9,312 (0.97)	963,490	0.06
1995	4,756 (0.48)	1,034 (0.11)	685 (0.07)	3,799 (0.39)	10,274 (1.04)	984,505	0.07
1996	5,415 (0.54)	1,086 (0.11)	756 (0.08)	3,971 (0.40)	11,228 (1.12)	1,004,230	0.08
1997	5,972 (0.59)	1,142 (0.11)	829 (0.08)	4,116 (0.41)	12,059 (1.19)	1,016,272	0.07
1998	6,572 (0.65)	1,188 (0.12)	902 (0.09)	4,254 (0.42)	12,916 (1.27)	1,016,791	0.08
1999	7,185 (0.71)	1,212 (0.12)	965 (0.10)	4,379 (0.43)	13,741 (1.36)	1,012,793	0.09
2000	7,813 (0.77)	1,255 (0.12)	1,054 (0.11)	4,502 (0.45)	14,624 (1.45)	1,008,481	0.09
2001	8,458 (0.84)	1,305 (0.13)	1,161 (0.12)	4,641 (0.46)	15,565 (1.55)	1,005,216	0.10
2002	9,083 (0.91)	1,354 (0.14)	1,241 (0.12)	4,747 (0.48)	16,425 (1.65)	994,836	0.10

continued on following page

Table 3. Prevalence of Children (aged 0–19) With a Developmental Disability in British Columbia 1986–2013

Year	Autism Spectrum Disorder (percent of total children in B.C.)	Down Syndrome (percent of total children in B.C.)	Fetal Alcohol Syndrome (percent of total children in B.C.)	Other Developmental Disability (percent of total children in B.C.)	Total Number of Children with a DD (percent of total children in B.C.)	Total Number of Children in B.C.	Absolute Percent Increase in Children With a DD (year over year)
2003	9,727 (0.99)	1,403 (0.14)	1,314 (0.13)	4,882 (0.50)	17,326 (1.76)	984,133	0.11
2004	10,437 (1.07)	1,444 (0.15)	1,394 (0.14)	4,982 (0.51)	18,257 (1.87)	976,030	0.11
2005	11,125 (1.15)	1,491 (0.15)	1,475 (0.15)	5,089 (0.52)	19,180 (1.97)	971,449	0.10
2006	11,770 (1.21)	1,546 (0.16)	1,552 (0.16)	5,159 (0.53)	20,027 (2.06)	970,121	0.09
2007	12,377 (1.28)	1,593 (0.16)	1,608 (0.17)	5,221 (0.54)	20,799 (2.15)	968,341	0.09
2008	12,994 (1.34)	1,654 (0.17)	1,631 (0.17)	5,260 (0.54)	21,539 (2.23)	967,538	0.08
2009	13,512 (1.40)	1,703 (0.18)	1,662 (0.17)	5,259 (0.54)	22,136 (2.29)	966,920	0.06
2010	13,899 (1.44)	1,736 (0.18)	1,672 (0.17)	5,262 (0.54)	22,569 (2.33)	966,860	0.04
2011	14,140 (1.46)	1,817 (0.19)	1,669 (0.17)	5,286 (0.55)	22,912 (2.37)	966,255	0.04
2012	14,328 (1.49)	1,892 (0.20)	1,696 (0.18)	5,305 (0.55)	23,221 (2.41)	963,780	0.04
2013	14,293 (1.49)	1,951 (0.20)	1,684 (0.18)	5,316 (0.55)	23,244 (2.42)	960,083	0.01

mental disability from 1986 to 2013 in the province of British Columbia. This information has not been available previously and will be important in future research and in program planning and funding decisions.

Using administrative data, this study found that in 2013 the prevalence of children with a developmental disability was estimated at 2.42% of the total population of children in British Columbia. The administrative health data also indicated that the prevalence of children with a developmental disability increased in British Columbia between 1986 and 2013 by

1.98%, largely due to an increase in the prevalence of children with ASD. However, there is also evidence that the increase in prevalence of children who have a developmental disability has slowed between 2010 and 2013.

For studies using administrative data, findings depend upon the data inputs which build the registry files (Broemeling et al., 2009). Therefore, limitations of the study findings include possible problems with the completeness and quality of the administrative data. In British Columbia, data from alternative funding arrangements (i.e., salaried physicians and nurse practitioners) and

Table 4. Comparison of Children With a Developmental Disability to Children Without a Developmental Disability in British Columbia

Variable	Autism Spectrum Disorder (birth data 1986–2013)	Down Syndrome (birth data 1986–2013)	Fetal Alcohol Syndrome (birth data 1986–2013)	Other Developmental Disabilities (birth data 1986–2013)	Comparison Cohort (children without a developmental disability born 1990–1995)
Sex					
Female	3,324 (22.02%)*	1,087 (45.86%)#	794 (43.22%)*	2,912 (45.32%)*	131,600 (48.91%)
Male	11,772 (77.98%)	1,281 (54.05%)	1,043 (56.78%)	3,510 (54.62%)	137,463 (51.09%)
Income Level at Birth					
Lowest	2,694 (24.22%)*	353 (22.70%)	520 (44.83%)*	944 (27.65%)*	57,527 (22.08%)
2 nd	2,391 (21.49%)	327 (21.03%)	243 (20.95%)	757 (22.17%)	55,449 (21.28%)
3 rd	2,187 (19.66%)	324 (20.84%)	144 (12.41%)*	683 (20.01%)	53,388 (20.49%)
4 th	2,124 (19.09%)	290 (18.65%)	134 (11.55%)*	439 (15.79%)*	50,919 (19.54%)
Highest	1,728 (15.53%)+	261 (16.78%)	119 (10.26%)*	491 (14.38%)§	43,264 (16.61%)
Health Authority at Birth					
Number (% of total births of children with a DD in the province)					
Interior	1,982 (17.53%)*	273 (16.87%)	215 (16.86%)	522 (14.53%)	41,779 (15.53%)
Fraser	3,867 (34.20%)^	605 (37.39%)	172 (13.49%)*	1,215 (33.83%)**	96,120 (35.72%)
Vancouver Coastal	2,611 (23.09%)	360 (22.25%)	153 (12.00%)*	916 (25.50%)*	60,228 (22.38%)
Island	2,078 (18.38%)*	240 (14.83%)	312 (24.47%)*	583 (16.23%)	43,229 (16.07%)
Northern	769 (6.80%)*	140 (8.65%)	423 (33.18%)*	365 (9.91%)	27,718 (10.30%)
* significantly different from the comparison group ($p < .0001$)					
# significantly different from the comparison group ($p = .0036$)					
+ significantly different from the comparison group ($p = .0029$)					
§ Significantly different from the comparison group ($p = .0059$)					
^ Significantly different from the comparison group ($p = .0009$)					
** Significantly different from the comparison group ($p = .0137$)					

First Nations medical systems are not included in the administrative data set. Therefore children using only these services will not have been included in this study.

Data used in this study rely upon diagnoses provided by physicians. Conclusions about the accuracy of diagnostic coding vary widely in the literature from good (Henderson, Shephard, & Sundararajan, 2006; Jetté, Reid, Quan, Hill, & Wiebe, 2010) to poor (Farzandipour, Sheikhtaheri, & Sadoughi, 2010; Jensen, Cooke, & Davis, 2013; Peabody, Luck, Jain, Bertenthal, & Glassman, 2004; Stausberg, Lehmann, Kaczmarek, & Stein, 2008) depending upon location of the study, disease or treatment examined, use of ICD-9 or ICD-10 codes and the study design. Use of medical coding for administrative data is also complicated by the problem of co-morbidity (Jensen et al., 2013; Kirby, 2002; Quan, Parsons, & Ghali, 2002). Kirby (2002) reported that mental retardation, cerebral palsy, hearing and vision impairment and epilepsy often co-occur but also that conditions that are co-morbidities are less likely to appear in medical records. In addition, diagnoses are restricted to the labels provided by ICD-9 and ICD-10 codes. The codes for fetal alcohol syndrome may particularly restrict the range of diagnoses possible as the definition that accompanies the ICD-9 and ICD-10 codes is fetal alcohol syndrome, not fetal alcohol spectrum disorder. Therefore, given the nature of administrative data, it is likely that this study under-estimates the prevalence of developmental disability, particularly of FASD.

Conclusion

In conclusion, this study found that 2.42% of children in B.C. in 2013 had a developmental disability. This population level information can help to address the lack of data regarding those who have a developmental disability and is important for future planning of programs and services for this vulnerable population. As Fujiura et al. (2010) stated: "What gets counted gets noticed."

Key Messages From This Article

People with disabilities. It is important to know the number of children who have a developmental disability so that programs and services can be planned appropriately.

Professionals. The overall prevalence of developmental disability in B.C. increased between 1986 and 2013. The prevalence of each of the four categories of developmental disability used in this study increased, with the largest increases in the ASD category.

Policymakers. Policy and services should be based upon up-to-date information on the prevalence of developmental disability, estimates of this information are available through administrative data.

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