

Using Administrative Health Data to Estimate the Prevalence of Children who have a Developmental Disability in British Columbia

Sandra Marquis, PhD

(no conflict of interest to declare)

Learning Objectives:

- Understand what administrative health data is and how it can be used
- Understand the limitations and strengths of administrative health data
- Learn what the prevalence of childhood developmental disability is as estimated by administrative health data In B.C.

Why were we interested?

- Part of a larger study on the health of parents and siblings of children who have a developmental disability
- No accurate information on the prevalence of children who have a developmental disability in B.C.

What already existed:

- National statistics on disability in Canada (2006) found 7,000 children aged 5-14 years in B.C. who had a developmental disability
- Counts of children in the B.C. school system with disabilities (2005/06) found 1.4% of students with some level of developmental disability
- Number of adults who have a developmental disability and receive services from the primary service organization in B.C. (2017) approx. 0.53% of the adult population
- The 2017 Canadian Survey on Disability estimated that there are 315,470 people who have a developmental disability in Canada (1.1% of the population)

Administrative health data:

- Produced by physicians for billing purposes
- Reported as ICD-9 and ICD-10 codes
- Data is owned by the B.C. Ministry of Health
- Anonymized data held in a secure research environment at Population Data B.C.
- Researchers can apply for 2 year access to the data

What we found:

- Prevalence for 1986-2013
- Overall there was an increase year by year in the number of children who have a developmental disability
- Largest increases were for diagnoses of ASD
- Higher than the often assumed 1% of the population

Table 1. Prevalence of Children (aged 0-19) with a DD in B.C. 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 DD (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
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

How is this useful?

- Setting goals
- Setting priorities
- Measuring progress
- Assessing outcomes

“what gets counted gets done”
(Fujiura et al. 2010, p. 244)

Strengths of the data:

- Administrative data is collected continuously at relatively short intervals
- Low cost
- Doesn't rely on estimates from surveys
- Doesn't rely on self reports
- Large sample sizes
- Includes rare diagnoses
- Includes control group
- Untapped source of large amounts of varied data
- Can be linked with other data sources

Limitations of the data:

- Relies on physician diagnoses connected to billing
- No control over definitions of developmental disability diagnoses
- Probably underestimates developmental disabilities which do not involve a “medical” diagnosis (i.e. FASD and ASD)
- Little detail about the severity of the developmental disability or co-occurring issues such as behaviour problems



References

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Contact: smarquis@uvic.ca