Trends in Autism Prevalence: Diagnostic Substitution Revisited

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BACKGROUND

Special education data provide a cost-effective way to examine changes over time in the prevalence of autism spectrum disorders (ASDs). Such data often include only the child's primary diagnosis, and it has been suggested that "diagnostic substitution" – whereby children with multiple diagnoses are categorized differently over time (Caronna & Hall, 2005) – may partially account for apparent increases in prevalence when using administrative data to study trends (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). There is little evidence to support this hypothesis, although studies to date have been limited to group-level comparisons. Examining whether individual children switched special education classifications would provide more direct evidence for or against the hypothesis that diagnostic substitution is a contributing factor to observed increases in autism prevalence.

OBJECTIVES

- To quantify the contribution of diagnostic substitution to changes in the administrative prevalence of autism, using individual-level data.
- To examine other factors that contributed to prevalence changes over the same time period.

METHODS

Data source

British Columbia (BC) Ministry of Education: collects information each year on all school age children who are assigned special education codes (includes public and private schools, as well as home-schooled children)/Edudata Canada: supports education research in BC and other regions of the country; the BC Ministry of Education makes its datasets available to Edudata Canada.

Study population

All BC school children 4 to 9 years of age who had an autism code (=autistic disorder) in at least one year between 1996 and 2004, inclusive (n=2198).

Analysis

The annual point prevalence of autism was calculated by dividing the number of children with an autism code as of September 30 (the prevalence date) by the total number of 4- to 9-year olds enrolled in the school system on the prevalence date. The contribution of diagnostic substitution, and other factors, to the yearly change in autism prevalence was determined as shown below.

X_A = # of 4-9 year olds with an autism code in year A; Y_A = # of 4-9 year olds in school in year A

X_{A+1} = # of 4-9 year olds with an autism code in year A+1; Y_{A+1} = # of 4-9 year olds in school in year A+1

Contribution of various factors to change in prevalence per 10,000 between Year A and Year A+1:
e.g. Diagnostic substitution = a/Y_{A+1} * 10,000

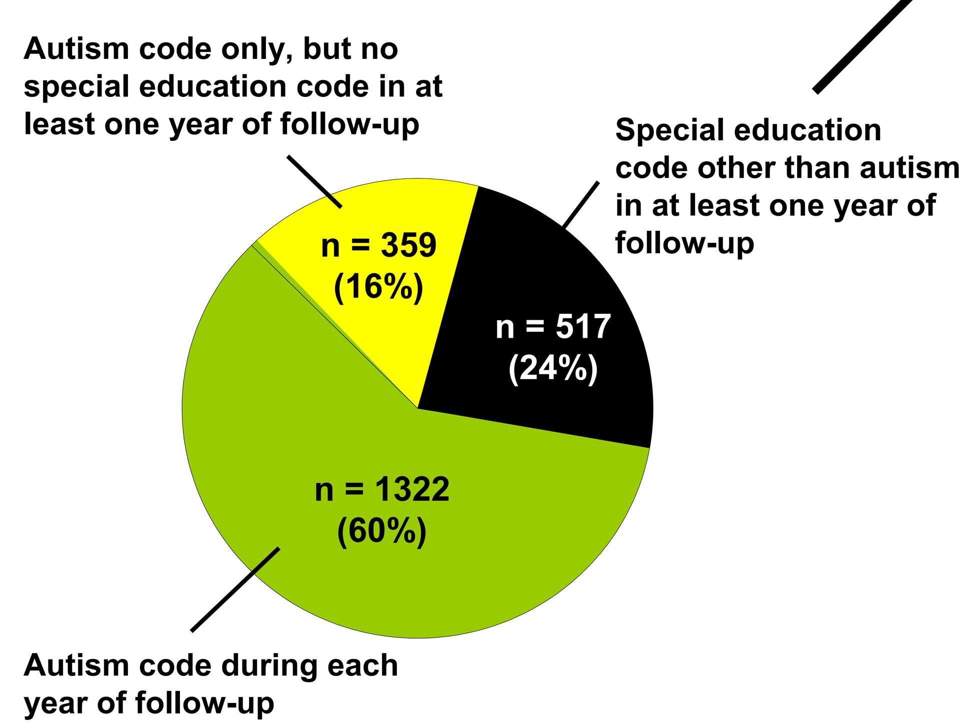
X_A

	Addition of cases			Loss of cases
Net diagnostic substitution (a-e)	Diagnostic substitution: # of children with a special education code other than autism in year A who had an autism code in year A+1	a	e	"Reverse" diagnostic substitution: # of children with an autism code in year A who had a special education code other than autism in year A+1
Net identification of previously undetected cases (b-f)	Identification of previously undetected cases: # of children with no special education code in year A who had an autism code in year A+1	b	f	Loss of autism code among previously identified cases: # of children with an autism code in year A who had no special education code in year A+1
Net cohort change (c-g)	Cases entering school system at age of mandatory school enrollment: # of children who weren't enrolled in school in Year A, who were at age of mandatory school enrollment and had an autism code in Year A+1	c	g	Previously identified cases who turned 10 years of age: # of children enrolled in school with an autism code in year A, who were no longer included in numerator for calculating prevalence in year A+1 because they were 10 years of age
Net migration (d-h)	In-migration: # of children who weren't enrolled in school in year A, who were above age of mandatory school enrollment and had an autism code in year A+1	d	h	Out-migration: # of children who had an autism code in Year A, who were younger than 10 years of age and no longer enrolled in school in Year A+1

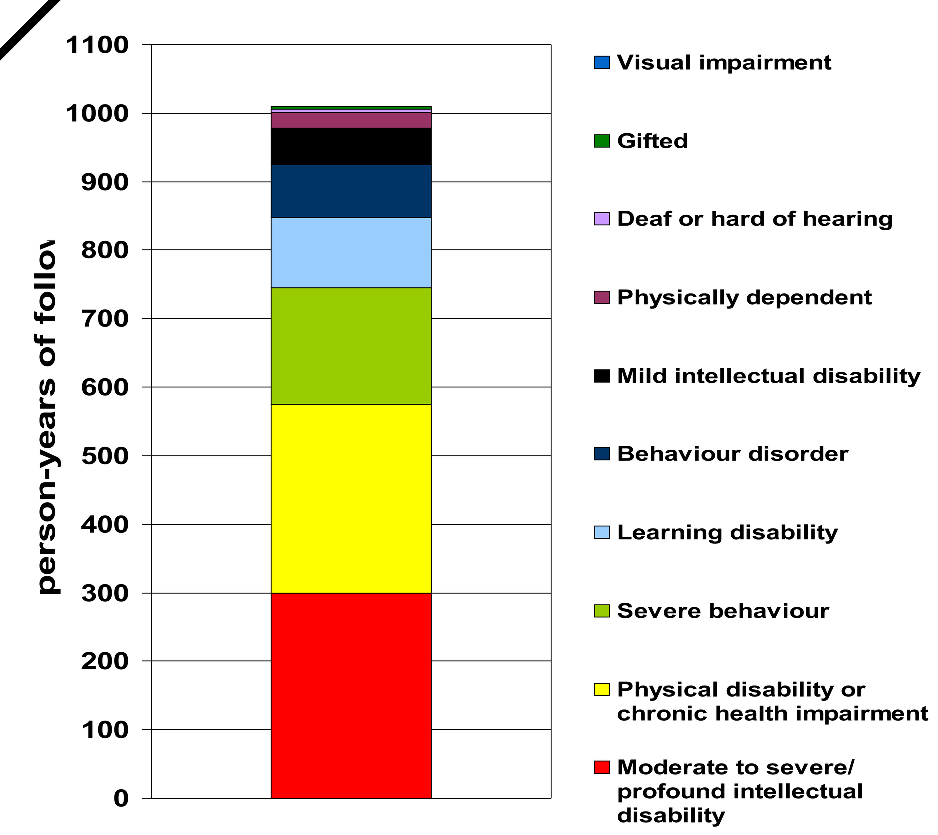
X_{A+1} (= X_A+a+b+c+d-e-f-g-h)

RESULTS

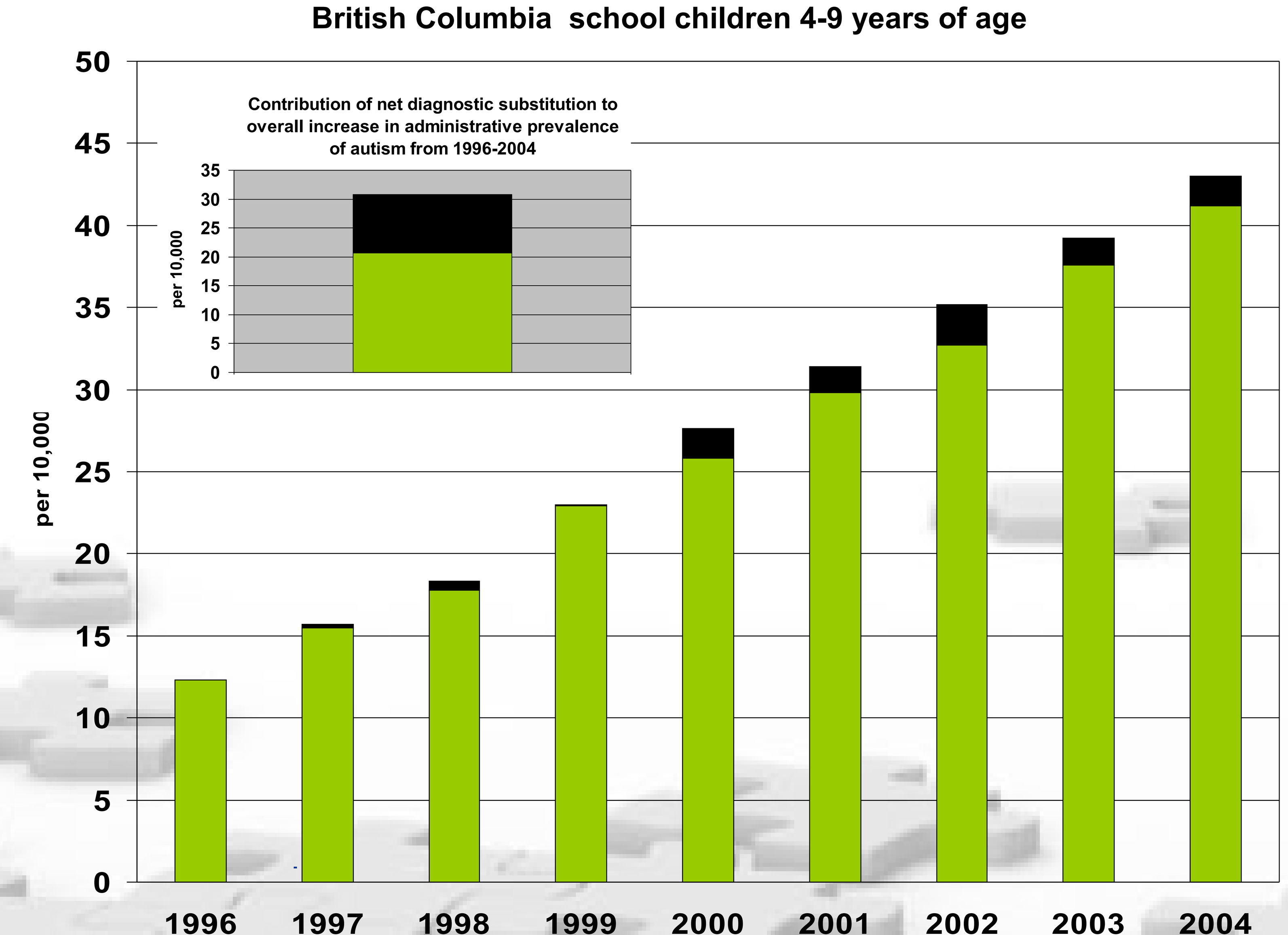
Pattern of special education code assignment among British Columbia school children 4-9 years of age who had an autism code in at least one year between 1996-2004



Frequency of other special education codes assigned

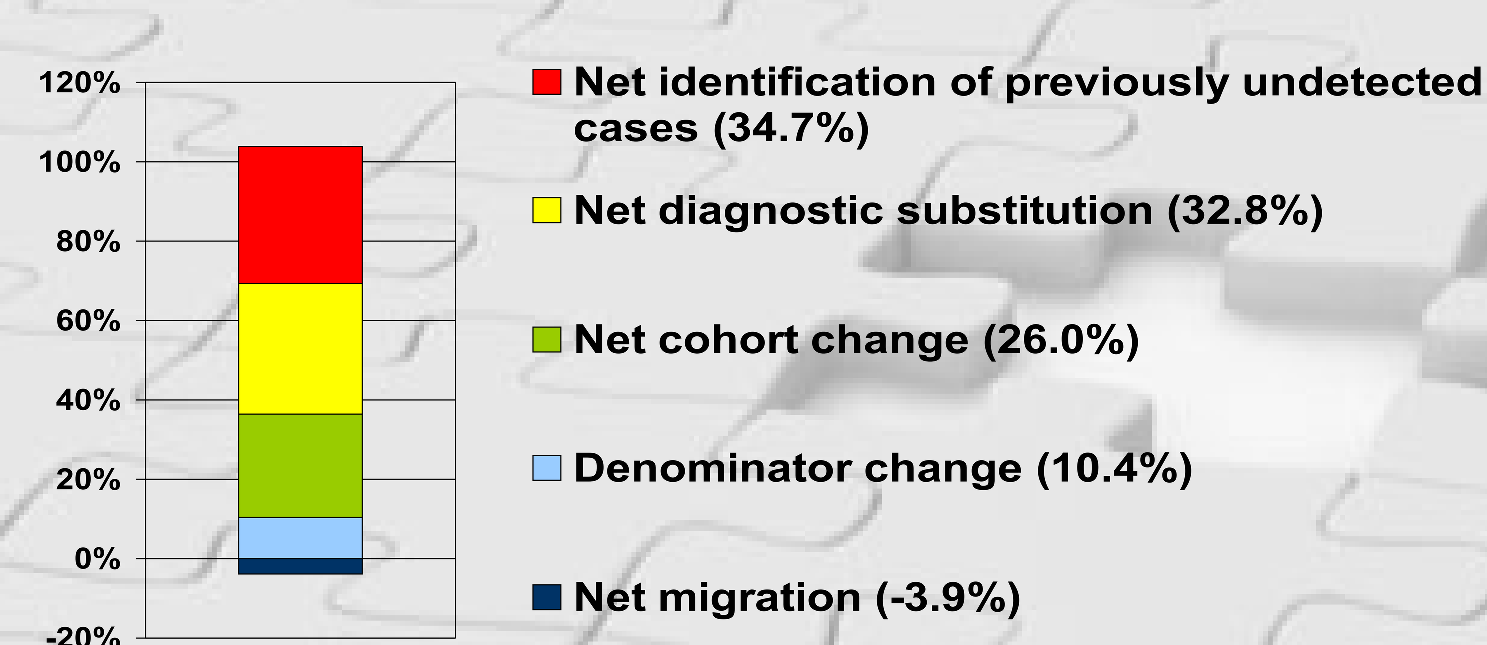


Contribution of diagnostic substitution to changes in the administrative prevalence of autism among British Columbia school children 4-9 years of age



Bar height on main graph indicates the annual point prevalence of autism. Bar height on inset shows the overall increase in prevalence between 1996 and 2004. Black area on both graphs indicates the contribution of diagnostic substitution to the change in prevalence.

Contribution of various factors to overall change in the administrative prevalence of autism among British Columbia school children 4-9 years of age from 1996-2004



DISCUSSION

Diagnostic substitution

- Accounted for a large percentage (51.9%) of the total increase in autism prevalence over the study period.
- Even when "reverse" diagnostic substitution was factored in, the net contribution of diagnostic substitution to the increase in autism prevalence was 10.1 per 10,000 (32.8% of the total increase).
  - This finding contradicts results from other studies where no evidence of diagnostic substitution was found (Gurney et al., 2003; Newschaffer et al., 2005).
  - It may have been difficult to detect diagnostic substitution if these data had been analyzed at the group level, since no one classification accounted for most of the non-autism special education codes assigned.

Other Factors

Identification of previously undetected cases

- The biggest contributor to the increase in prevalence over the study period was identification of previously undetected cases, i.e. children who had no special education code in the previous year who were assigned an autism code in the following year.
  - There is no way of knowing whether this was because children were not diagnosed until a later age, families were not willing to accept the diagnosis of autism, or there was some other reason for the discrepancy. Under-diagnosis in past years has been suggested as one reason why the prevalence of autism appears to be increasing (Gurney et al., 2003).

Cohort change

- The proportion of children who were assigned an autism code upon entering the school system at the age of mandatory school enrollment increased over the study period, from 4.1 per 10,000 (1997) to 6.6 per 10,000 (2004).
- Net cohort change, based on the difference between this proportion and the proportion of children who were previously included in the numerator for prevalence but were no longer included in the following year because they turned 10 years of age, accounted for 26.0% of the increase in prevalence over the study period.
  - Differential migration of preschool children with autism into BC over the study period could be one explanation for the increase attributable to cohort change.
  - It is also possible that alterations in diagnostic and referral patterns, or an increase in the real risk of autism, may underlie the increase attributable to this factor.

CONCLUSION

Interpreting changes in autism prevalence based on administrative data requires careful consideration of the above-noted factors.

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