



The Use of Medically Required Dental Services by Youth with Intellectual/Developmental Disabilities in British Columbia, Canada

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ABSTRACT

Introduction: The literature indicates that youth with intellectual/developmental disabilities (IDD), such as Down syndrome or autism, have poor oral health. A number of factors influence their oral health, including the use of medically required dental treatments.

Methods: This paper describes the first use of population-level administrative health data to examine the use of medically required dental services by youth with IDD compared with youth without IDD in Canada.

Results: Youth with IDD had 4–9 times the odds of a medically required dental treatment compared with youth without IDD. Odds varied with age and type of IDD.

Conclusion: Youth with IDD used medically required dental services to a greater extent than youth without IDD. Use of medically required dental treatments by youth with IDD declined with age; this may indicate greater difficulty accessing services when youth transition from pediatric to adult services. These findings provide baseline information on the use of medically required dental treatments and can contribute to future assessments of dental services for youth with IDD.

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There is evidence that both children^{1,2} and adults³⁻⁵ who have intellectual/developmental disabilities (IDD) have poorer oral health than children and adults without IDD. The reasons for poorer oral health may include lack of access to appropriate dental care and delay in required dental care.⁶ The lack of professional care and early intervention can result in disease progression and the need for more invasive treatments, such as surgery and the use of general anesthesia.⁷ In a population of people with a variety of disabilities, Figueira⁸ found that tooth loss was greater for those who had fewer than 1 annual visit for dental care compared with those with more frequent dental care.

For people with IDD, problems accessing dental services can be because of a lack of trained and experienced dental professionals,^{3,9} lack of specialized dental anesthesiologists, long waitlists and inaccessible or inappropriate physical facilities.^{3,10} Scarcity of dentists and dental specialists in rural areas can affect access.¹¹ Access to dental care is also affected by the knowledge and experience of caregivers who support people with IDD.⁹ Social determinants of health factors, such as poverty¹ and the lack of insurance coverage or public dental plans,^{3,12} also affect access to dental services for people with IDD.

In addition, individual factors, such as the type and severity of IDD, behaviour and comorbidities, can impact both daily oral hygiene and access to dental care.^{3,13} Caregiver burden and caregiver age can affect the provision of daily oral hygiene.¹⁴ Lindemann¹⁵ found that among people with IDD, those who brushed their own teeth had fewer missing teeth than those who did not; those with a dentist of record had fewer decayed and more filled teeth; and people living at home with family or friends had a significantly lower DMFT index (decayed, missing and filled teeth) than those living independently or in facilities.

Life-course transitions have been identified as among the most difficult times for the health care of people with IDD.¹⁶ Biggs and Carter¹⁷ found that physical well-being in youth with IDD aged 13–21 years was associated with age; an increase in age predicted lower ratings of physical well-being. Nathenson and Zablotsky¹⁸ found a decline in the use of health care services, except for emergency services, by autistic youth transitioning to adult services.

For people in British Columbia (BC) receiving income or disability assistance, some of the costs of routine dental care are covered by direct payment to dentists through the Ministry for Social Development and Poverty Reduction.¹⁹ For adults receiving a disability allowance, the maximum coverage is \$1000 over 2 calendar years. For children, the coverage is \$2000 over 2 calendar years, plus \$1000 over the same period to cover the cost of dental treatment in a hospital or special clinic while receiving general anesthesia.²⁰ Many advocates argue that these services are underfunded resulting in the majority

of dentists in the province charging fees in addition to the coverage supplied through provincial social services.^{21,22}

The cost of additional dental care may be covered by provincial health services, but it must be deemed “medically required.” Services considered medically required in the general population are dental treatments that cannot be provided in a dental office and are complex enough to require treatment in a hospital or specialized clinic, often under anesthesia. However, routine dental treatments may be deemed medically required for youth with IDD if dentists do not feel able to treat them because of physical or behavioural issues. Few dental clinics are specifically designed for the routine care of people with IDD; therefore, for some people with IDD, hospital admission and use of general anesthesia may be required for routine dental care.²³

Addressing the gaps in service and providing adequate dental care for people with IDD is hampered by a lack of information. Most studies in this area have been small and have used convenience sampling; therefore, generalizing their results to larger populations is limited.⁵ As Lim⁵ states: “without sufficient robust data... it can be difficult to enact further change to address these [dental] health disparities” (p. 68). To address the lack of information, this study used population-level data to examine medically required dental care in youth with IDD in BC. The objectives were to compare such care for youth with and without IDD and for 2 age groups: 15–19 years and 20–24 years. In addition, the use of medically required dental care was examined for youth with various types of IDD. This is the first study in Canada to use population-level administrative health data to assess dental services among youth with IDD.

Methods

The study population was youth aged 15–24 years diagnosed with IDD. The comparison cohort was all other youth of the same age in BC in 2010–2019.

Population-level health data were obtained from the British Columbia Ministry of Health via Population Data BC, which provides researchers with linkages of administrative data and access to data extracts.²⁴ Population Data BC linked 3 data sets: a central consolidation file with demographic information on all individuals in BC²⁵; Medical Services Plan (MSP) payment files, which contain information for all fee-for-service care provided by physicians in BC²⁶; and the hospital separation file, which contains information on all hospital admissions in BC.²⁷ Data were linked using individual unique and study-specific codes that allow people to be anonymously identified across data sets. Diagnoses were identified using the International Classification of Diseases 9th revision (ICD-9) codes in MSP data and the International Classification of Diseases

10th revision (ICD-10) codes in hospital data. When patients visit a fee-for-service clinic or hospital, their diagnosis is assigned an ICD-9 or ICD-10 code for billing purposes. The BC Ministry of Health provided approval for data access and the University of British Columbia provided ethics approval (#H20-03028).

People with IDD were identified using ICD-9 and ICD-10 codes as described in the algorithm developed by Lin et al.²⁸ These codes identify a wide range of IDD (**Appendix A**). To ensure the identification of as many youth with IDD as possible, medical records from 1986–2019 were examined, and people with IDD were traced forward or backward in time. A diagnosis of IDD was either a primary diagnosis or a secondary diagnosis noted by physicians when the child visited the doctor. Type of IDD was subdivided into fetal alcohol syndrome (FAS), autism, Down syndrome and “other,” i.e., IDD not included in the first 3 groups. In addition, youth with multiple IDD diagnoses (e.g., autism plus Down syndrome or FAS plus autism) were grouped together as a separate variable and compared with youth with a single IDD diagnosis.

To examine the transition of youth from pediatric to adult services, subsets of the larger cohort were formed. In the subsets, youth were identified as 15 years old in 2010, 16 years old in 2011, 17 years old in 2012 etc., to 24 years old in 2019. The subset of youth with IDD was compared with a subset of the comparison cohort; the 2 groups were matched for age, sex and time (these subsets are referred to in the remainder of this paper as the transition subsets).

Dental diagnoses were identified using ICD-9 and ICD-10 codes (**Appendix A**) in MSP and hospital data. Dental diagnoses were services including dental exams, preoperative assessments for dental procedures and in-hospital procedures primarily for impacted teeth, abnormal tooth development and dental caries.

Overall descriptive statistics were reported for the larger group of youth with IDD and the comparison group; variables included sex, receipt of an MSP subsidy, income quintile and the health authority area in which the youth lived. The overall 10-year use of medically required dental services was reported for youth with IDD and for the comparison group. The smaller transition groups were also compared.

Programming and data analyses were conducted using Statistical Analysis System (SAS) v. 9.4 (SAS Institute Inc. Cary, NC, USA). Chi-square tests and t tests were used to compare proportions and means between youth with and without IDD. Multiple logistic regression was used to examine the binary outcome of having versus not having a medically required dental treatment, comparing youth with IDD to youth without IDD. SAS proc logistic fitted logistic regression models and estimated parameters for maximum likelihood using a Fisher’s scoring algorithm. Odds ratios (ORs) and 99% confidence intervals (CIs) were obtained. ORs were

calculated for both the large group and the subgroups, comparing youth with and without IDD. Variables available in the administrative health data and used in OR calculations included sex, age, type of IDD, 5 geographic health authority areas and income quintile. In addition, MSP subsidy levels were available and were used as an indication of poverty. In BC, before 2020, MSP premiums were paid by individuals or employer plans. People with a low income received a provincial subsidy to cover their MSP costs. People with missing data were excluded from the study; there was no identified pattern to the missing data.

The difference-in-differences technique was used to compare mean number of dental visits of youth with and without IDD over time as the youth transitioned from pediatric to adult health services at age 19. Difference-in-differences methods compare changes over time in an outcome between exposed and comparison groups using repeated measures generalized linear models.²⁹ The analyses compare population averages between 2 periods for exposed and comparison groups.

Results

Descriptive statistics can be found in **Table 1**. Using all 10 years of data, 20 591 youth with IDD were identified. This represents 1.57% of the population of youth aged 15–24 in BC in 2010–2019. The cohort with IDD included a greater proportion of males than the comparison group. In the IDD group, 35% of patients received an MSP subsidy compared with 18% of the comparison cohort. A greater proportion of people with IDD occurred in the lowest income quintile compared with the group without IDD. In the transition subset of youth with IDD, the distribution of sex, income and receipt of an MSP subsidy was similar to that of the larger groups.

When hospital data were examined, 2 dental issues (caries and impacted teeth) were among the 5 most frequent reasons for admission to hospital for youth with IDD. For youth without IDD, dental issues did not appear among the 20 most frequent reasons for hospital admission; for this group, the 5 most frequent reasons for admission were related to giving birth and mental health.

Using all 10 years of data and the large group of youth with IDD, we found that, holding all other variables constant, youth with IDD had an OR of 7.002 (99% CI 6.727–7.287) for a medically required dental visit compared with youth without IDD (**Table 2**). In addition, holding all other variables constant, females had greater odds of a medically required dental visit compared with males, and youth receiving an MSP supplement had greater odds than those who did not receive an MSP supplement.

For youth aged 15 in 2010, the odds of having a medically required visit for a dental issue were 9.420 times greater for youth with IDD than for youth without IDD (Table 3). As youth aged, the odds declined but still remained higher in youth with IDD compared with those without IDD.

In the unadjusted repeated measures ANOVA difference-in-differences, the mean number of diagnoses per person for medically required dental issues decreased significantly over time for youth both with and without IDD (Table 4). The difference in decrease between the 2 cohorts was significant.

Using all 10 years of data and the large group of youth with IDD and holding all other variables constant, results showed that compared with youth with Down syndrome, youth with FAS (1.263, 99% CI 1.027–1.552), and youth with “other” diagnoses (1.348, 99% CI 1.126–1.614) had greater odds of a medically required oral health care visit (Table 5). Youth with autism did not have significantly different odds of a medically required dental visit compared with youth with Down syndrome. Youth with multiple IDD diagnoses had greater odds of a medically required oral health care visit compared to youth with a single IDD diagnosis (2.386, 99% CI 2.153–2.644).

Table 1: Descriptive statistics for youth with and without intellectual/developmental disabilities (IDD) in British Columbia, 2010–2019.

Variable	Youth with IDD, no. (%)	Youth without IDD, no. (%)
Total (% of all youth)	20 591 (1.57)	1 293 791 (98.43)
Male	14 138 (68.66)*	656 159 (50.72)*
Female	6 452 (31.33)*	637 627 (49.28)*
Receiving an MSP subsidy (at any time during 2010–2019)	7 207 (35.00)*	231 674 (17.91)*
Neighbourhood income quintile†		
1st (lowest)	4 666 (22.76)	250 276 (19.58)
2nd	4 157 (20.28)	253 980 (19.87)
3rd	3 893 (18.99)	258 905 (20.26)
4th	3 984 (19.43)	245 465 (19.21)
5th (highest)	3 615 (17.63)	246 276 (19.27)
Health authority†		
Interior	4 666 (22.76)	187 379 (14.52)
Fraser	4 157 (20.28)	493 978 (38.29)
Vancouver Coastal	3 893 (18.99)	325 166 (25.20)
Vancouver Island	3 984 (19.43)	185 487 (14.38)
Northern	3 615 (17.63)	82 999 (6.43)
Type of IDD (number and % of persons with an IDD)		
Autism	11 305 (54.90)	
Down syndrome	967 (4.70)	
FAS	1 955 (9.49)	
Other	6 364 (30.91)	
People with Multiple IDD Diagnoses‡	3 549 (17.24)	

* $p < 0.001$.

† Measured at the last time the person is identified in the data.

‡ ≥ 2 types of IDD, e.g., Down syndrome + autism. Includes those in individual diagnosis groups.

Table 2: Odds of dental issues among British Columbia youth with intellectual/developmental disabilities (IDD) ($n = 20\,591$) compared with those without IDD ($n = 1\,293\,791$).

Variable	Odds ratio (95% CI)	Probability, p
Youth with IDD vs. youth without IDD	7.002 (6.727–7.287)	< 0.0001
Sex (female vs. male)	1.642 (1.607–1.677)	< 0.0001
Receipt of an MSP subsidy vs. no MSP subsidy	1.627 (1.590–1.664)	< 0.0001
Income quintile		
Lowest vs. highest	1.023 (0.990–1.057)	0.1746
2nd vs. highest	0.972 (0.940–1.005)	0.09192
3rd vs. highest	0.984 (0.952–1.017)	0.3310
4th vs. highest	1.070 (1.035–1.106)	< 0.0001
Health authority		
Interior vs Vancouver Coastal	1.296 (1.253–1.341)	< 0.0001
Fraser vs Vancouver Coastal	1.019 (0.990–1.048)	0.20263
Vancouver Island vs Vancouver Coastal	1.726 (1.673–1.781)	< 0.0001
Northern vs Vancouver Coastal	0.977 (0.930–1.027)	0.3602

Table 3: Number and odds of youth with intellectual/developmental disabilities (IDD) having ≥ 1 medically required visits for dental issues compared with youth without IDD, by age, British Columbia, 2010–2019.

Year, age	Youth with IDD, no. (%)	Youth without IDD, no. (%)	Odds ratio (99% CI)*
2010, 15 years	54 (5.44)	297 (0.66)	9.420 (6.976–12.719)
2011, 16 years	46 (4.63)	371 (0.82)	6.075 (4.426–8.338)
2012, 17 years	54 (5.44)	400 (0.89)	6.734 (5.001–9.067)
2013, 18 years	43 (4.33)	391 (0.87)	5.679 (4.093–7.879)
2014, 19 years	54 (5.44)	409 (0.91)	6.685 (4.973–8.988)
2015, 20 years	41 (4.13)	368 (0.82)	5.473 (3.924–7.632)
2016, 21 years	36 (3.63)	384 (0.85)	4.835 (3.403–6.870)
2017, 22 years	33 (3.32)	402 (0.89)	4.249 (2.950–6.120)
2018, 23 years	39 (3.93)	354 (0.79)	5.398 (3.840–7.588)
2019, 24 years	30 (3.02)	268 (0.60)	5.518 (3.748–8.124)

* $p < 0.0001$ for all odds ratios.

Table 4: Difference-in-differences analyses of visits for dental issues among British Columbia youth with and without intellectual/developmental disabilities (IDD), 2010–2019.

	Youth with IDD	Youth without IDD	<i>p</i> value
Mean no. diagnoses in youth aged 15–19 in 2010–2014	4.57	0.31	< 0.0001
Mean no. diagnoses in youth aged 19–24 in 2015–2019	2.59	0.16	< 0.0001
Difference in mean no. diagnoses between time periods	–1.98	–0.15	
Effect of time			< 0.0001
Effect of time × cohort			< 0.0001

Table 5: Odds ratios for dental issues among youth with intellectual/developmental disabilities (IDD), British Columbia, 2010–2019 (*n* = 20 591).

Variable	Odds ratio (95% CI)	Probability, <i>p</i>
Sex (female vs. male)	1.440 (1.327–1.563)	< 0.0001
Receipt of an MSP subsidy	0.690 (0.624–0.762)	< 0.0001
Type of IDD		
FAS vs. Down syndrome	1.263 (1.027–1.552)	0.0270
Autism vs. Down syndrome	1.016 (0.840–1.230)	0.8690
Other vs. Down syndrome	1.348 (1.126–1.614)	0.0011
People with multiple IDD diagnoses vs. people with a single IDD diagnosis	2.386 (2.153–2.644)	< 0.0001
Health authority		
Interior vs. Vancouver Coastal	0.735 (0.647–0.834)	< 0.001
Fraser vs. Vancouver Coastal	0.953 (0.856–1.061)	0.3824
Vancouver Island vs. Vancouver Coastal	0.910 (0.806–1.028)	0.1310
Northern vs. Vancouver Coastal	0.727 (0.613–0.860)	0.0002

Discussion

Previous studies have shown that people with IDD have poorer oral health compared with people without IDD. The current study used administrative health data to examine medically required dental visits of youth with IDD. In both the large cohort of youth with IDD and the transition subset, youth with IDD had significantly greater odds of a medically required dental visit compared with youth without IDD. This finding persisted as the youth aged from 15 to 24 years. This finding may be the result of lack of access to routine dental cleaning and services for youth with IDD.

Type of IDD affects the odds of medically required dental visits: youth with FAS, or other diagnoses had greater odds of a medically required dental visit compared with youth with Down syndrome. This finding may indicate problems with access to routine services that are compounded by low income, severity of IDD and/or behaviour problems. In addition, people with some IDD types may be receiving more support for dental needs than people with other IDD types. For example, challenges associated with dental care and autism have received significant attention and specific services have been developed in BC for this group.²³

Visits for medically required dental issues decline with age in youth with and without IDD. The reasons for this decline are unknown. It may indicate an improvement in the oral health of people with IDD as they age; however, there is no evidence of this in the literature. Pradhan et al.³⁰ reported similar dental issues for people with IDD aged 18–24 and those aged 24–34 and an increase in dental issues for those aged 35–44. Alternatively, the decline in medically required dental treatment with age found in this study may indicate that dental issues become increasingly neglected as people with IDD leave pediatric health care services. Reasons for this may include the lack of specialty dental services for adults with IDD and the decrease in funding for dental services for adults compared with children (\$2000/2-year period for children reduced to \$1000/2-year period for adults).

Poor oral health is a concern among people with IDD. As well as loss of teeth³¹ and dental caries, dental problems have been linked to untreated pain.^{32,33} Untreated pain can be an unrecognized cause of behaviour issues in non-verbal people with IDD.^{32,33} In people with IDD, oral microbial load is also a risk factor for respiratory infections, particularly pneumonia,³⁴ and may contribute to the risk of sepsis.³⁵

Dental health is both a contributor to overall health and a result of sociocultural determinants of health and health care inequities.³⁶ People with disabilities are particularly vulnerable to inequities in dental health.³⁷ Solutions to this include increased funding for dental care for disabled people and training for specialist dentists.³⁸ At the

same time, people with IDD must be included in dental research, clinical trials and subsequent policymaking to ensure that dental care is inclusive and equitable.³⁷ As suggested by Faulks et al.,³⁹ one means of ensuring the inclusion of people with IDD and consideration of the social determinants of health may be to use the World Health Organization International Classification of Functioning, Disability and Health⁴⁰ as a means of measuring oral health.

Strengths of this Study

The use of population-level administrative health data ensured that a relatively large number of an otherwise small population of people was obtained. The data also allowed examination of a variety of IDD types, analysis of the effect of time and anonymity.

Limitations of the Study

The administrative health data examined in this study are used for medical billing purposes. The data do not provide information about access to routine dental visits or dental cleaning. Information about routine dental care is essential in understanding the dental care needs of people with IDD. The data also did not provide information about severity of IDD or behaviour problems that can affect access to dental care, nor did this study examine the living situation of people with IDD and caregiver capacity to provide support. In addition, measures of income used in this study were not precise. Findings in this study may vary in other parts of Canada, as funding models for dental care vary between provinces. To better understand issues of dental care and IDD, future research in this area should include information on routine dental care. In addition, the authors recommend that, where possible, information on this subject be collected from other provinces.

Conclusion

Data on the oral health status of Canadians in general are scarce, particularly for populations with IDD. This study has provided valuable information about the use of dental services for youth with IDD in BC. Further information about routine dental services is needed to examine access issues for people with IDD. However, the greater use of non-routine medically required dental services by youth with IDD may reflect their poor oral health and limited access to routine dental services. Access to routine dental services in BC could be improved with better financial coverage for dental care for this population, improved training of dentists and dental professionals and provincial policies that ensure access to routine dental care for people with IDD.

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Appendix A: ICD-9 and ICD-10 codes.

Diagnostic codes for intellectual/developmental disabilities.

ICD-9	
299	Pervasive development disorders (e.g., autism)
317	Mild mental retardation
318	Moderate severe and profound mental retardation
319	Unspecified mental retardation
7580-7583	Chromosomal anomalies for which a developmental disability is typically present (e.g., Down syndrome, cri-du-chat syndrome)
7585	Other conditions due to autosomal anomalies
7588	Other conditions due to chromosome anomalies
7589	Conditions due to anomaly of unspecified chromosome
7595	Tuberous sclerosis
75981	Other and unspecified congenital anomalies: Prader–Willi
75983	Other and unspecified congenital anomalies: Fragile X
75989	Other and unspecified congenital anomalies: other (e.g., Menkes disease, Laurence–Moon–Biedl, Rubinstein–Taybi syndrome, etc.)
76071	Foetal alcohol syndrome
76077	Foetal hydantoin syndrome
ICD 10	
F700	Mild mental retardation with the statement of no, or minimal, impairment of behaviour
F701	Mild mental retardation, significant impairment of behaviour requiring attention or treatment
F708	Mild mental retardation, other impairments of behaviour
F709	Mild mental retardation without mention of impairment of behaviour
F710	Moderate mental retardation with the statement of no, or minimal, impairment of behaviour
F711	Moderate mental retardation, significant impairment of behaviour requiring attention or treatment
F718	Moderate mental retardation, other impairments of behaviour
F719	Moderate mental retardation without mention of impairment of behaviour
F720	Severe mental retardation with the statement of no, or minimal, impairment of behaviour
F721	Severe mental retardation, significant impairment of behaviour requiring attention or treatment
F728	Severe mental retardation, other impairments of behaviour
F729	Severe mental retardation without mention of impairment of behaviour
F730	Profound mental retardation with the statement of no, or minimal, impairment of behaviour
F731	Profound mental retardation, significant impairment of behaviour requiring attention or treatment
F738	Profound mental retardation, other impairments of behaviour
F739	Profound mental retardation without mention of impairment of behaviour
F780	Other mental retardation with the statement of no, or minimal, impairment of behaviour
F781	Other mental retardation, significant impairment of behaviour requiring attention or treatment
F788	Other mental retardation, other impairments of behaviour
F789	Other mental retardation without mention of impairment of behaviour

continued ►

Appendix A: ICD-9 and ICD-10 codes.

F790	Unspecified mental retardation with the statement of no, or minimal, impairment of behaviour
F791	Unspecified mental retardation, significant impairment of behaviour requiring attention or treatment
F798	Unspecified mental retardation, other impairments of behaviour
F799	Unspecified mental retardation without mention of impairment of behaviour
F840	Childhood autism
F841	Atypical autism
F843	Other childhood disintegrative disorder
F844	Overactive disorder associated with mental retardation and stereotyped movements
F845	Asperger's syndrome
F848	Other pervasive developmental disorders
F849	Pervasive developmental disorder, unspecified
Q851	Tuberous sclerosis
Q860	Foetal alcohol syndrome
Q861	Foetal hydantoin syndrome
Q871	Aarskog, Prader–Willi, de Lange, Seckel, etc.
Q878	Other
Q90	Down syndrome
Q91–Q939	Chromosomal abnormalities not elsewhere classified
Q971	Female with more than three chromosomes
Q992	Fragile X syndrome
Q998	Other specified chromosomal abnormalities

Diagnostic codes for dental conditions.

ICD-9	
03A	Pre-operative assessment (dental)
V722	Dental examination
ICD 10	
K00	Disorders of tooth development and eruption
K01	Embedded and impacted teeth
K02	Dental caries
K03	Other diseases of teeth
K04	Diseases of pulp and periapical tissues

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