

# Access to Dental Care for Persons with Developmental Disabilities in Ontario

*Anjani Koneru, DMD, MSc, FRCD(C); Michael J. Sigal, DDS, Dip Paedo, MSc, FRCD(C)*

## Contact Author

*Dr. Koneru*  
*Email: [anjani.koneru@usask.ca](mailto:anjani.koneru@usask.ca)*



## ABSTRACT

**Objectives:** This study was undertaken to determine the proportion of persons primarily with developmental disabilities who encounter difficulties accessing dental care in Ontario, to identify perceived barriers to accessing dental care and to determine if persons with disabilities and their caregivers believe that oral health is important.

**Methods:** Community organizations providing services mainly to persons with developmental disabilities in Ontario were recruited to circulate a questionnaire to their members by mail or the Internet. Fourteen organizations mailed out a total of 1,755 paper questionnaires in autumn 2006, of which 420 (23.9%) were returned; in addition, 236 Internet questionnaires were returned.

**Results:** Of the 656 paper and Internet responses, 634 were deemed valid. Most of the respondents had developmental disabilities. Almost three-quarters of respondents (464 [73.2%]) reported being able to access dental services in Ontario. Personal (internal) factors were more likely to represent barriers to dental care than external factors.

**Conclusions:** The majority of persons with disabilities and most caregivers believed that oral health is important for overall health.

For citation purposes, the electronic version is the definitive version of this article: [www.cda-adc.ca/jcda/vol-75/issue-2/121.html](http://www.cda-adc.ca/jcda/vol-75/issue-2/121.html)

Disability has often been described as a physiological deficit. Current concepts of disability, however, are based on social models, which describe disability in terms of functional limitations experienced by a person because of environmental and social barriers.<sup>1</sup> More specifically, a person with a disability has been defined as anyone who has or has had an impairment causing a long-term adverse effect upon his or her ability to perform daily activities typical for the person's stage of development and cultural environment.<sup>2</sup> Disabilities may be visible, such as physical impairments, or invisible, such as learning or memory deficits. A developmental disability is defined as impairment of one or

more functions controlled by the brain, with onset during the developmental period from birth to 22 years of age, causing a functional limitation in 3 or more areas of life such as self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.<sup>3</sup> In Canada in 2006, 14.3% of the population had a disability.<sup>4</sup> The number of persons with disabilities is increasing because of population growth, increased reporting, aging of the population and more accurate and sensitive methods of detection and diagnosis.<sup>5-7</sup> In Ontario in 2006, 15.5% of the population, approximately 1.8 million people, had a disability,<sup>4</sup> up from 13.2% in 2001. The

most commonly reported disabilities in Ontario relate to mobility (10.5%), agility (10.3%) and pain (10.9%). The least common disabilities are developmental disabilities (0.6%), and disabilities related to memory (1.8%), speech (2.0%) and learning (2.7%).<sup>4</sup>

Most persons with disabilities live in community settings and rely on agencies in the community for services to meet their health care needs. Despite community efforts, many persons with disabilities have poor oral health<sup>8</sup> and are at risk for poorer overall health and lower quality of life than persons without such conditions.<sup>9</sup> Poor oral health may stem from dental disease that goes untreated because of improper diagnosis or poor access to dental care.<sup>10</sup>

Access to professional dental care has been defined as the ability to obtain and make use of dental services.<sup>11</sup> Studies of access to dental care for persons with disabilities have differed in the ease or difficulty experienced in obtaining care. In some studies, 35%–80%<sup>12–15</sup> of persons with disabilities had no difficulty accessing dental care, whereas in other studies, nearly 50%–70%<sup>16,17</sup> experienced difficulty. Reasons cited for disparities in accessing care are related to availability, proximity and affordability of dental services; attitudes and beliefs of caregivers, dentists and persons with disabilities; and environmental and legal issues. Few studies have looked at access to dental care for persons with developmental disabilities in Ontario. Kenny and McKim<sup>18</sup> found that 15.5% of children with Down syndrome and 25.9% of children with cerebral palsy experienced difficulty obtaining dental care. More recently, a survey in Ontario revealed that 89% of general dentists treated persons with disabilities, but less than 60% treated persons with developmental disabilities.<sup>19</sup> The objectives of this study were to determine the proportion of persons primarily with developmental disabilities who experience difficulty accessing dental care in Ontario, to identify significant perceived barriers to accessing dental care and to determine if persons with disabilities and their caregivers believe that oral health is an important component of overall health.

## Methods

Ethics approval was obtained from the Health Sciences Research Ethics Board at the University of Toronto on June 12, 2006.

A 19-item self-administered questionnaire was developed and made available in paper and electronic (online) formats (**Appendix 1**). The questionnaire specified that in cases where the potential respondent was unable to complete the self-administered questionnaire, the caregiver should answer the questions on the respondent's behalf. A sample-size calculation was conducted for a power of 80%, with sampling error set at 5% using the probability proportional to population size method. This

yielded a target sample size of 384, based on 1.8 million persons with disabilities in Ontario.

Community organizations providing services mainly to persons with developmental disabilities were enlisted to help with the distribution of questionnaires. In all, 121 organizations were contacted, of which 22 agreed to help. The organizations were asked to advertise the study by email, phone, website, bulletin boards and newsletters and, if possible, to directly distribute paper questionnaires to their members or clients. Each organization was asked to randomly select members from its mailing list and to mail pre-assembled packages containing a copy of the questionnaire, a cover letter and a self-addressed prestamped envelope to the selected members. One set of packages was sent, with no reminders. The electronic (online) questionnaire was available at the website of the faculty of dentistry at the University of Toronto and the websites of 2 community organizations.

A total of 1,755 questionnaire packages were mailed by 14 of the community organizations between September and November 2006. Responses were accepted between September 2006 and January 2007. Completed paper questionnaires and responses submitted electronically were reviewed for completeness. Valid returned questionnaires were coded and entered into a Statistical Package for the Social Sciences (SPSS) 15.0 database. Data analysis consisted of calculation of simple frequencies and percentages. Comparisons and associations were explored with  $\chi^2$  testing. Independent factors with a statistically significant association with difficulty or ease of obtaining dental care were included in a binomial logistic regression model using the "Enter" method. All independent variables were coded as dichotomous, such that the reference categories represented the absence of the variable in question. Statistically significant differences were defined as  $p < 0.05$ .

## Results

Of 1,755 paper questionnaires distributed by mail, 420 (23.9%) were returned. In addition, 101 self-printed questionnaires and 135 online responses were submitted; the response rate could not be calculated for these additional responses. Of the 656 completed questionnaires received, 22 were considered invalid, which left 634 valid responses for data analysis. Questionnaires were considered invalid if a disability was not identified and difficulty obtaining dental care could not be determined.

For 484 of the responses, the caregiver completed the questionnaire on behalf of the person with a disability (CG-PWD group); 91 of these were submitted online. Self-reporting persons with disabilities (SR-PWD group) completed 150 questionnaires, of which 43 were submitted online. Of the 484 caregivers submitting responses, 350 (72.3%) were female. Caregivers were between the ages of 23 and 87 years (mean 47.6 years). Just

**Table 1** Types of disabilities or conditions represented by persons with disabilities living in Ontario who responded to a survey about access to dental care<sup>a</sup>

Diagnosis	Group; no. (%) of respondents	
	CG-PWD (n = 484)	SR-PWD (n = 150)
Autism	63 (13.0)	8 (5.3)
Cerebral palsy	33 (6.8)	19 (12.7)
Down syndrome	199 (41.1)	11 (7.3)
Developmental delay	272 (56.2)	67 (44.7)
Other (physical disability, psychiatric disability, brain injury)	92 (19.0)	75 (50.0)

CG-PWD = caregiver responded on behalf of a person with a disability, SR-PWD = self-reported response by a person with a disability.  
<sup>a</sup>Some respondents had more than one diagnosed condition.

**Table 2** Types of dental coverage reported by persons with disabilities in study sample

Type of coverage	Group; no. (%) of respondents	
	CG-PWD (n = 484)	SR – PWD (n = 150)
None	18 (3.7)	20 (13.3)
Private insurance only	112 (23.1)	24 (16.0)
Ontario Disability Support Program only	294 (60.7)	97 (64.7)
Private insurance and Ontario Disability Support Program	46 (9.5)	4 (2.7)
Other form of government-sponsored coverage	8 (1.7)	4 (2.7)
No response	6 (1.2)	1 (0.7)

CG-PWD = caregiver responded on behalf of a person with a disability, SR-PWD = self-reported response by a person with a disability.

over half of the persons with disabilities represented by these caregivers were male (258/484 [53.3%]); the mean age of this group of persons with disabilities was 30.3 years (2–75 years). Well over half of those in the SR-PWD group were female (89/150 [59.3%]); these respondents were older than those in the CG-PWD group (mean age 41.4 years, age range 17–81 years). The majority of persons with disabilities in the CG-PWD group lived in parental or family homes (260/484 [53.7%]) or group homes (193/484 [39.9%]), whereas more than half of those in the SR-PWD group lived independently (86/150 [57.3%]). Most persons with disabilities in the CG-PWD group had developmental disabilities associated with conditions such as Down syndrome, autism spectrum disorder and cerebral palsy. Those in the SR-PWD group were more likely to have physical and psychiatric disabilities (**Table 1**). In total, 455/484 (94%) of persons with disabilities in the CG-PWD group had a developmental disability, a much greater proportion than in the SR-PWD group (79/150 [52.7%]).

Most of the persons with disabilities in both groups had dental coverage from the Ontario Disability Support Program (ODSP), but a greater proportion of those in the SR-PWD group had no insurance (**Table 2**). The majority of both groups had seen a dentist within the past year (423/484 [87.4%] of those in the CG-PWD group and 116/150 [77.3%] in the SR-PWD group). Almost half saw the dentist every 6 months (257/614 [41.9%]; pooled data), whereas 5.5% (34/614; pooled data) saw the dentist only for emergencies. Most saw a general dentist (450/611 [73.6%]; pooled data), but those in the CG-PWD group were more likely to see a specialist (149/471 [31.6%]) than those in the SR-PWD group (12/140 [8.6%]). Most persons with disabilities (pooled data) attended private dental clinics (452/617 [73.3%]), followed by hospital clinics (128/617 [20.7%]) and public health clinics (47/617 [7.6%]). Nearly 318/620 [51.3%] (pooled data) did not require special modifications to receive dental treatment, but 144/620 [23.2%] required sedation and 139/620 [22.4%] required general anesthesia. Most persons with disabilities had received basic dental services, but fewer

**Table 3** Types of dental treatment received by persons with disabilities in study sample

Treatment	Group; no. (%) of respondents	
	CG-PWD (n = 478)	SR-PWD (n = 149)
Examination	452 (94.6)	142 (95.3)
Radiography	364 (76.2)	134 (89.9)
Fluoride application	278 (58.2)	103 (69.1)
Cleaning	432 (90.4)	137 (91.9)
Oral hygiene instruction	182 (38.1)	65 (43.6)
Sealants	54 (11.3)	17 (11.4)
Fillings	277 (57.9)	115 (77.2)
Extraction	221 (46.2)	79 (53.0)
Stainless steel crown	19 (4.0)	4 (2.7)
Esthetic crown and bridge	12 (2.5)	14 (9.4)
Braces or appliances	43 (9.0)	32 (21.5)
Dentures	15 (3.1)	11 (7.4)
Bleaching	1 (0.2)	7 (4.7)
Root canal therapy	39 (8.2)	35 (23.5)
Dental implants	6 (1.3)	6 (4.0)

CG-PWD = caregiver responded on behalf of a person with a disability, SR-PWD = self-reported response by a person with a disability.

**Table 4** Barriers limiting access to dental care reported by persons with disabilities

Barrier	Group; no. (%) of respondents	
	CG-PWD (n = 484)	SR-PWD (n = 150)
Inadequate dental facilities	30 (6.2)	3 (2.0)
Inadequate dental training	47 (9.7)	4 (2.7)
Other reasons dentist unable to treat	30 (6.2)	10 (6.7)
Cost	63 (13.0)	41 (27.3)
Fear	89 (18.4)	22 (14.7)
Lack of perceived need	23 (4.8)	12 (8.0)
Poor tolerance	108 (22.3)	12 (8.0)
Transportation problems	43 (8.9)	25 (16.7)
Time factors	15 (3.1)	8 (5.3)
Distance factors	31 (6.4)	17 (11.3)
Difficulty with physical access	16 (3.3)	13 (8.7)

CG-PWD = caregiver responded on behalf of a person with a disability, SR-PWD = self-reported response by a person with a disability.

had undergone major restorative treatment (**Table 3**). The majority of people in both groups reported dental needs that required treatment (375/484 [77.5%] of those in the CG-PWD group and 97/150 [64.7%] of those in the SR-PWD group). Almost half (228/484 [47.1%]) of the

CG-PWD group had difficulty communicating dental pain, whereas 26 (17.3%) of the 150 people in the SR-PWD group reported such difficulty.

Similar proportions of the CG-PWD group (359/484 [74.2%]) and the SR-PWD group (105/150 [70.0%])

**Table 5** Independent variables associated with ease or difficulty in obtaining dental care

Independent variable <sup>a</sup>	p value ( $\chi^2$ test)	% with difficulty accessing care vs. % with no difficulty <sup>b</sup>	OR (95% CI)
<b>CG-PWD group</b>			
Down syndrome	0.034	20.3 vs. 79.7	0.63 (0.41–0.97)
Severe developmental delay	0.001	38.9 vs. 61.1	2.22 (1.73–3.62)
Difficulty communicating pain	0.001	35.4 vs. 64.6	2.80 (1.81–4.32)
Needs special modifications	0.001	34.9 vs. 66.0	2.68 (1.72–4.16)
Caregiver aged 55 or older	0.046	14.9 vs. 85.1	0.40 (0.21–0.77)
Living in western Ontario	0.005	12.2 vs. 87.8	0.37 (0.18–0.76)
Private insurance only	0.004	15.2 vs. 84.8	0.45 (0.25–0.78)
Government coverage only	0.021	29.0 vs. 71.0	1.69 (1.08–2.66)
<b>SR-PWD group</b>			
Difficulty communicating pain	0.014	50.0 vs. 50.0	2.88 (1.21–6.85)
Needs special modifications	0.001	47.5 vs. 52.5	4.40 (2.07–9.35)
No dental coverage	0.038	50.0 vs. 50.0	2.69 (1.03–7.00)

OR = odds ratio, CI = confidence interval, CG-PWD = caregiver responded on behalf of a person with a disability, SR-PWD = self-reported response by a person with a disability.

<sup>a</sup>Characteristics of persons with disabilities.

<sup>b</sup>Data represent the percentage of each group with the indicated factor.

**Table 6** Odds ratios for independent predictors associated with difficulty obtaining dental care as experienced by people with disabilities (logistic regression)

Predictor	p value	OR (95% CI)
<b>CG-PWD group</b>		
Difficulty communicating pain	0.020	1.98 (1.12–3.51)
Needs special modifications	0.001	2.56 (1.45–4.52)
<b>SR-PWD group</b>		
Needs special modifications	0.001	4.67 (2.16–10.09)

OR = odds ratio, CI = confidence interval, CG-PWD = caregiver responded on behalf of a person with a disability, SR-PWD = self-reported response by a person with a disability.

reported no difficulty accessing dental care. The most common barriers to accessing dental care cited by both groups (pooled data) were an inability to tolerate/cooperate with treatment (120/634 [18.9%]), fear of the dentist (111/634 [17.5%]), cost (104/634 [16.4%]) and transportation difficulties (68/634 [10.7%]) (Table 4). In the CG-PWD group many factors were associated with difficulty accessing dental care, including receipt of government dental coverage, having severe developmental delay, having difficulty communicating pain and needing special modifications to receive dental treatment. In the SR-PWD group, a lack of dental coverage was also associated with difficulty accessing dental care (Table 5). In

**Table 7** Agreement with statement “oral or dental health is important for overall health” as reported by survey participants

Response	Group; no. (%) of respondents	
	Caregivers <sup>a</sup> (n = 484)	Persons with a disability (n = 150)
Strongly agree	384 (79.3)	100 (66.7)
Agree	45 (9.3)	36 (23.8)
Indifferent	0 (0)	7 (4.8)
Disagree	1 (0.2)	2 (1.4)
Strongly disagree	54 (11.2)	5 (3.4)

<sup>a</sup>Based on caregivers' own beliefs.

both groups, the strongest predictor of difficulty accessing dental care was requirement for special modifications to receive dental treatment (Table 6). With regard to beliefs, most caregivers (429/484 [88.6%]) and persons with disabilities (136/150 [90.5%]) believed that oral health was an important part of overall health (Table 7).

## Discussion

The majority of persons with disabilities in the present study were able to access dental care in Ontario (73.2%, based on pooled data from both the CG-PWD and SR-PWD groups), with 87.4% of those in the CG-PWD group and 77.3% of those in the SR-PWD group having visited



the dentist within the past year. These rates are better than the general rate of 70% reported for all Ontarians in 2003<sup>20</sup> and are similar to those reported in other studies<sup>14,15,21</sup> looking at dental service utilization by persons with disabilities. For both persons with disabilities and the general population, the utilization rate for dental services lags behind that for medical services (94%).<sup>22</sup>

The finding that 26.8% of persons with disabilities had difficulty obtaining dental care in Ontario (based on pooled data from the CG-PWD and SR-PWD groups) falls within the range of values reported in other studies: 14.8% in Iowa,<sup>23</sup> 19% in Ontario,<sup>18</sup> 27.1% in France,<sup>8</sup> and 40% in Florida.<sup>14</sup> Many factors appear to influence access to dental care. Personal (internal) factors, such as anxiety about dental procedures, inability to tolerate dental treatment, apathy about dental care and inability to communicate dental pain, were more often cited as barriers to obtaining dental care than environmental (external) factors, such as cost, physical access, transportation and dentist-related factors. Dental anxiety has been shown to lead to avoidance behaviours such as cancelling or missing dental appointments. In 2005, 15% of Canadians reported dental anxiety,<sup>24</sup> and 42%–54% of Canadians have demonstrated an interest in undergoing sedation or general anesthesia for dental procedures. These values correspond with the present study, in which 45.6% of persons with disabilities reported needing sedation (23.2%) or general anesthesia (22.4%). As expected, greater difficulty obtaining dental care was associated with a requirement for these special modifications (CG-PWD group: OR 2.56, 95% CI 1.45–4.52; SR-PWD group: OR 4.67, 95% CI 2.16–10.09).

Less than 10% of both the CG-PWD and SR-PWD groups reported that a dentist was unwilling to provide treatment. Such refusals were due to reasons similar to those reported in other studies,<sup>14,19</sup> such as inadequate training, inadequate facilities and refusal to accept government programs such as the ODSP. Inadequate dentist training and inadequate facilities were reported by a greater proportion of those in the CG-PWD group than in the SR-PWD group, which may be related to the greater proportion of persons with severe developmental disabilities in the CG-PWD group. These people may be more likely to require the use of special modifications, such as protective stabilization, sedation or general anesthesia, for which dentists need additional training. Dentists' refusal to accept remuneration from the ODSP was reported by 7 respondents overall. The ODSP payment schedule is lower than the Ontario Dental Association's suggested fee guide, which may pose a disincentive for dentists; for example, current ODSP rates may not cover dentists' overhead expenses.<sup>19</sup> For the general population in Canada, having private dental insurance and having a higher income were associated with greater utilization of dental services.<sup>20</sup>

Most persons with disabilities reported having dental needs that required treatment (77.5% of those in the CG-PWD group and 64.7% of those in the SR-PWD group). These reported needs might have represented needs for ongoing care, such as periodic examination and cleaning, or unmet needs arising from lack of treatment or failure of previous treatment to meet patients' expectations. Nearly all persons with disabilities in the present study had had a dental examination and prophylactic treatment, but they were more likely to have had extractions and received fillings than to have undergone procedures such as application of sealants or major restorative treatment such as crown and bridge placement, endodontic therapy or orthodontic treatment. This finding is similar to those of other studies<sup>21,25</sup> and may be related to factors such as patients' or caregivers' beliefs, tolerance of treatment, oral hygiene, cost-related factors and dentists' beliefs.

Most persons with disabilities and most caregivers felt that oral health was an important part of overall health. Belief systems can affect whether individuals seek dental treatment and whether caregivers seek dental treatment for the people for whom they are responsible. Previous studies have shown that when informal caregivers have poor oral health, the people for whom they are responsible are more susceptible to dental neglect.<sup>23,26</sup> In the present study, no relationship was found between caregivers' opinion or the opinions of persons with disabilities and access to dental care or frequency of dental visits. For the minority who believed that oral health was not integral to overall health, this belief did not seem to prevent utilization of dental services, which might have reflected a need for emergency dental treatment.

The findings of the present study, though encouraging, should be reviewed with caution. This study was susceptible to sampling, nonresponse and recall biases. Most of the respondents lived in the Greater Toronto Area, and so would have had easier access to dental services than people living in isolated communities.<sup>20</sup> Those responding to the survey might also have been more motivated and aggressive in seeking dental care and might therefore have been more successful in obtaining care, as has been reported in other studies.<sup>8</sup> In addition, many organizations that provide services for persons with disabilities declined to help with the distribution of questionnaires, and some might have been overlooked. The present study had a greater proportion of respondents with Down syndrome, because of the specific community organizations that agreed to help with distribution of the questionnaires. Given national prevalence rates, more people would be expected to have autism spectrum disorder<sup>27</sup> or cerebral palsy<sup>28</sup> than Down syndrome or neural tube defects.<sup>29</sup>

The response rate of 23.9%, although low, falls within the range reported by other similar studies: 21%,<sup>12</sup> 31.2%,<sup>15</sup> 58.3%,<sup>8</sup> and 63.5%.<sup>21</sup> The response rate was calculated from the number of paper questionnaires distributed and returned and therefore does not account for the questionnaires submitted online. It was impossible to establish the denominator for a response rate calculation for the online questionnaire, because it was freely accessible from several websites (rather than being distributed by private email messages sent to prospective participants). It is also possible that some respondents who received the questionnaire in paper format chose instead to complete the questionnaire online. The questionnaire was in English, and the vocabulary chosen did not accommodate all literacy levels. In addition, the questionnaire was not available in large font or audio format. These shortcomings may have discouraged some potential respondents from participating in the study. Attempts to improve the response rate, such as reminder mailings or follow-up contacts, were not pursued, as many of the community organizations had limited resources and could only perform the initial mailing. Finally, no information was available about nonresponders because of privacy concerns. The need to respect privacy also meant that the validity of the responses received could not be verified through dental records or by contacting the respondents. For these and other reasons, it is difficult to gather meaningful data about persons with developmental disabilities. Therefore, although the ideal methodology for future studies would be a random telephone survey, followed by a review of dental records and/or a clinical examination, this approach may be impractical because of the small proportion of Ontarians with a developmental disability, privacy issues and other logistical concerns. Therefore, although this study's findings may create the illusion that access to dental care for Ontario residents with developmental disabilities is comparable to that of the general population, one must keep in mind the limitations that might suggest otherwise.

## Conclusions

Most persons with developmental disabilities in Ontario appear to be able to access dental care; however, those who require special modifications such as general anesthesia to receive dental treatment reported the greatest difficulty in obtaining care. Personal (internal) factors such as dental anxiety and inability to cooperate were more strongly associated with difficulty accessing dental care than environmental factors. The majority of persons with disabilities and of caregivers believed that oral health is important for overall health. ➤

## THE AUTHORS



**Dr. Koneru** is an assistant professor at the College of Dentistry, University of Saskatchewan, Saskatoon, Saskatchewan.



**Dr. Sigal** is dentist-in-chief at Mount Sinai Hospital and a professor in and head of pediatric dentistry, University of Toronto, Toronto, Ontario.

**Acknowledgements:** The authors would like to acknowledge the assistance of Dr. Howard Tenenbaum, Dr. David Locker and Dr. Clive Friedman and the following organizations in supporting this study: Community Living (CL) Toronto, CL Ontario, CL Algoma, CL Owen Sound, Harmony Centre for CL, CL Windsor, CL North Hastings, CL Thunder Bay, CL Meaford, CL Stratford and Area, CL Campbellford/Brighton, CL Oshawa-Clarington, CL Brantford, CL Superior Greenstone Association, Spina Bifida and Hydrocephalus Association of Ontario, Ontario Federation of Cerebral Palsy, Developmental Services Access Centre-Kitchener, Down Syndrome Association of Toronto, Down Syndrome Association of Ontario, Adult Protective Services Ontario, Epilepsy Ontario, Autism Partnership, Autism Ontario, Canadian Abilities Foundation, Geneva Center, and Participation House.

**Correspondence to:** Dr. Anjani Koneru, College of Dentistry, University of Saskatchewan, 105 Wiggins Road, Saskatoon, SK S7N 5E4.

The authors have no declared financial interests.

This article has been peer reviewed.

## References

- World Health Organization. ICF introduction. ICF: International classification of functioning, disability and health. 2001. Available: [www.who.int/classifications/icf/en](http://www.who.int/classifications/icf/en).
- Merry AJ, Edwards DM. Disability part 1: the Disability Discrimination Act (1995) — implications for dentists. *Brit Dent J* 2002; 193(4):199–201.
- Accardo PJ, Whitman BY. Dictionary of developmental disabilities terminology. 2nd ed. Baltimore, Md: Paul H. Brookes Publishing Co; 2002.
- Statistics Canada. Participation and activity limitation survey 2006: analytical report. Ottawa: Statistics Canada Catalogue no. 89-628-XIE, 2007. Available: [www.statcan.ca/english/freepub/89-628-XIE/89-628-XIE2007002.pdf](http://www.statcan.ca/english/freepub/89-628-XIE/89-628-XIE2007002.pdf) (accessed 2009 Feb 17).
- Nunn JH. The dental health of mentally and physically handicapped children: a review of the literature. *Community Dent Health* 1987; 4(2):157–68.
- Waldman HB, Perlman SP. Providing general dentistry for people with disabilities: a demographic review. *Gen Dent* 2000; 48(5):566–9.
- World Health Organization. Concept note: world report on disability and rehabilitation. 2006. Available: [www.who.int/disabilities/publications/dar\\_world\\_report\\_concept\\_note.pdf](http://www.who.int/disabilities/publications/dar_world_report_concept_note.pdf) (accessed 2009 Feb 17).
- Allison PJ, Hennequin M, Faulks D. Dental care access among individuals with Down syndrome in France. *Spec Care Dentist* 2000; 20(1):28–34.
- Brennan DS, Spencer AJ, Roberts-Thomson KF. Tooth loss, chewing ability and quality of life. *Qual Life Res* 2008; 17(2):227–35. Epub 2007 Dec 14.
- Hennequin M, Faulks D, Roux D. Accuracy of estimation of dental treatment need in special care patients. *J Dent* 2000; 28(2):131–6.
- Guay AH. Access to dental care: the triad of essential factors in access-to-care programs. *J Am Dent Assoc* 2004; 135(6):779–85.
- Al Agili DE, Roseman J, Pass MA, Thornton JB, Chavers LS. Access to dental care in Alabama for children with special needs: parents' perspectives. *J Am Dent Assoc* 2004; 135(4):490–5.
- Bourke LF, Jago JD. Problems of persons with cerebral palsy in obtaining dental care. *Aust Dent J* 1983; 28(4):221–6.
- Burtner AP, Jones JS, McNeal DR, Low DW. A survey of the availability of dental services to developmentally disabled persons residing in the community. *Spec Care Dent* 1990; 10(6):182–4.
- McDermott RE, El-Badrawy HE. A survey of parents' perception of the dental needs of their handicapped child. *J Can Dent Assoc* 1986; 52(5):425–7.

16. Finger ST, Jedrychowksi JR. Parents' perception of access to dental care for children with handicapping conditions. *Spec Care Dentist* 1989; 9(6):195–9.
17. Russell GM, Kinirons MJ. A study of the barriers to dental care in a sample of patients with cerebral palsy. *Community Dent Health* 1993; 10(1):57–64.
18. Kenny DJ, McKim JS. Dental care demand for mongoloid and cerebral palsied children. *J Can Dent Assoc (Tor)* 1971; 37(7):270–4.
19. Loeppky WP, Sigal MJ. Patients with special health care needs in general and pediatric dental practices in Ontario. *J Can Dent Assoc* 2006; 72(10):915. Available: [www.cda-adc.ca/jcda/vol-72/issue-10/915.html](http://www.cda-adc.ca/jcda/vol-72/issue-10/915.html).
20. Millar WJ. Dental consultations. In: Health Reports. Vol. 16, No. 1. Statistics Canada Catalogue no: 82-003-XIE. p. 41; 2004. Available: <http://dsp-psd.pwgsc.gc.ca/Collection-R/Statcan/82-003-XIE/0010482-003-XIE.pdf> (accessed 2009 Feb 17).
21. Kaye PL, Fiske J, Bower EJ, Newton JT, Fenlon M. Views and experiences of parents and siblings of adults with Down syndrome regarding oral health care: a qualitative and quantitative study. *Brit Dent J* 2005; 198(9):571–8.
22. Sanmartin C, Houle C, Berthelot JM, White, K. Access to health care services in Canada, 2001. Ottawa: Statistics Canada Catalogue no. 82-575-XIE; 2002. Available: [www.statcan.ca/english/freepub/82-575-XIE/2002001/pdf/report.pdf](http://www.statcan.ca/english/freepub/82-575-XIE/2002001/pdf/report.pdf) (accessed 2009 Feb 17).
23. McGrady J, Kanellis M, Warren JJ, Levy SM. Access to dental care for group home residents in Iowa. In: Mouradian W, Porter A, eds. Proceedings. Promoting oral health of children with neurodevelopmental disabilities and other special health needs. Seattle, WA: Center on Human Development and Disability, University of Washington; 2001 May 4–5. p. 71–2. Available: [www.healthychild.ucla.edu/nohpc/National%20Oral%20Health%20Policy%20Center/Publications/Promoting%20Oral%20Health.pdf](http://www.healthychild.ucla.edu/nohpc/National%20Oral%20Health%20Policy%20Center/Publications/Promoting%20Oral%20Health.pdf) (accessed 2009 Feb 17).
24. Chanpong B, Haas DA, Locker D. Need and demand for sedation or general anesthetic in dentistry: a national survey of the Canadian population. *Anesth Prog* 2005; 52(1):3–11.
25. Pezzementi ML, Fisher MA. Oral health status of people with intellectual disabilities in the southeastern United States. *J Am Dent Assoc* 2005; 136(7):903–12.
26. Grant E, Carlson G, Cullen-Erickson M. Oral health for people with intellectual disability and high support needs: positive outcomes. *Spec Care Dentist* 2004; 24(2):70–9.
27. Autism Society Canada. What is autism spectrum disorder? Available: [www.autismsocietycanada.ca/pdf\\_word/info\\_ASC%27swhatisautisminfo sheet\\_27\\_June\\_07\\_e.pdf](http://www.autismsocietycanada.ca/pdf_word/info_ASC%27swhatisautisminfo sheet_27_June_07_e.pdf) (accessed 2009 Feb 17).
28. Murphy N, Such-Neibar T. Cerebral palsy diagnosis and management: the state of the art. *Curr Probl Pediatr Adolesc Health Care* 2003; 33(5):146–69.
29. Health Canada. Congenital anomalies in Canada — a perinatal health report, 2002. Ottawa: Minister of Public Works and Government Services Canada, 2002. Available: [www.phac-aspc.gc.ca/publicat/cac-acc02/pdf/cac2002\\_e.pdf](http://www.phac-aspc.gc.ca/publicat/cac-acc02/pdf/cac2002_e.pdf) (accessed 2009 Feb 17).



**Appendix 1:** Questionnaire

**Part I.**

**Instructions:** Mark an “X” to answer the following questions:

1.  Consent obtained from legal guardian or person with disability who is able to make own legal decisions.
2. ‘Persons with disabilities’ is defined as any person or persons who has a physical, intellectual, mental or medical impairment that significantly limits one or more activities of daily living or the ability to function within their respective peer group.

Are you a person with a disability?    \_\_\_ YES    \_\_\_ NO

3. Age of person with disability: \_\_\_\_\_    Gender:    \_\_\_ M    \_\_\_ F

4. Caregiver is defined as the primary person in charge of caring for a person with a disability, usually a family member or a designated health care professional.

Are you a caregiver? \_\_\_ YES    \_\_\_ NO (Age: \_\_\_\_\_    Gender:    \_\_\_ M    \_\_\_ F)

**If you are a person with a disability please answer from your own experience, but if you are a caregiver please answer according to the person you care for.**

5. What are the first 3 digits of the postal code of the town or city that you or the person you care for live in?

Town/city (Name or first 3 digits of postal code): \_\_\_\_\_

6. What living situation do you or the person you care for live in?

\_\_\_ with parent/guardian    \_\_\_ in foster care    \_\_\_ independent living

\_\_\_ group home    \_\_\_ institution    \_\_\_ other (specify): \_\_\_\_\_

7. Please indicate the types of conditions that you or the person you care for have (please check all that apply):

\_\_\_ Autism

\_\_\_ Developmental delay

   \_\_\_ Mild    \_\_\_ Moderate    \_\_\_ Severe

\_\_\_ Down syndrome

\_\_\_ Cerebral palsy

\_\_\_ Other, please specify: \_\_\_\_\_

8. Do you or the person you care for have any dental (oral health) needs that require dental treatment?

\_\_\_ YES    \_\_\_ NO

9. Have you or the person you care for experienced difficulties in obtaining dental care in your community?

\_\_\_ YES    \_\_\_ NO

10. Do you, the person with the disability, or the person you care for have private dental insurance?

\_\_\_ YES    \_\_\_ NO

11. If you or the person you care for does not have private insurance, but dental care is paid for by a government-sponsored program, please indicate which program:

- Ontario Disability Support Program (ODSP)     Ontario Works (OW)  
 Children in Need of Treatment (CINOT)

12. What types of dental treatment have you or the person you care for received in the past?

- |  |   |  |
|--|---|--|
| <input type="checkbox"/> Examination             | <input type="checkbox"/> Fillings                 | <input type="checkbox"/> Braces or appliances        |
| <input type="checkbox"/> X-rays                  | <input type="checkbox"/> Extractions              | <input type="checkbox"/> Dentures or partial denture |
| <input type="checkbox"/> Fluoride                | <input type="checkbox"/> Sealants                 | <input type="checkbox"/> Bleaching                   |
| <input type="checkbox"/> Cleaning                | <input type="checkbox"/> Oral hygiene instruction | <input type="checkbox"/> Root canals                 |
| <input type="checkbox"/> Esthetic crowns/bridges | <input type="checkbox"/> Stainless steel crowns   | <input type="checkbox"/> Dental implants             |

13. When did you, or the person you care for, have a last dental visit?

- within one year     greater than one year

14. What was the overall length of time of the last dental appointment you or the person you care for underwent? Please check the appropriate box.

	Under 30 min	30 min–1 hr	1 hr–2 hr	Other (specify)
Time in waiting room				
Time with hygienist				
Time with dentist				

15. If you or the person you care for has a regular dentist:

a. How often do you or the person you care for go?

- emergency only     every 3 mos.     every 6 mos.     every 12 mos.

Other (please specify) \_\_\_\_\_

b. How far is the dentist from your place of residence or the place of residence of the person you care for?

- within 10 km     within 10–50 km     within 50–100 km     greater than 100 km

c. Is the dentist:

- a general dentist     a specialist?

d. Is the dental clinic:

- a private office     a public community health clinic     a hospital?

16. Do you or the person you care for have difficulty communicating dental pain?

- YES     NO

17. Do you or the person you care for require any special modifications to receive dental care?

- |  |  |
|--|--|
| <input type="checkbox"/> No                                | <input type="checkbox"/> Protective support or restraint |
| <input type="checkbox"/> Sedation                          | <input type="checkbox"/> Wheelchair transfer             |
| <input type="checkbox"/> General anesthetic                | <input type="checkbox"/> Other (please list: _____)      |
| <input type="checkbox"/> Special chair, backrest, headrest |  |

— Persons with Disabilities —

18. If you or the person you care for has difficulty accessing or does not access dental care, please indicate the reasons why: Please **check** the appropriate box to indicate if the reason is: **not a reason, a minor reason or a major reason.**

Reason	Not a reason	Minor reason	Major reason
Dentist unwilling to treat because of inadequate facilities.			
Dentist unwilling to treat because inadequately trained in treating people with disabilities.			
Dentist unwilling to treat because of other reason. Please specify:			
Cost or financial difficulty.			
Afraid of the dentist.			
Nothing wrong with teeth, dental treatment not important or necessary.			
Unable to sit in dental chair or cooperate with dentist.			
Transportation difficulty.			
No time.			
Dental clinic too far away.			
Dental clinic building difficult to access, or parking poor.			
Other reasons. Please specify:			

**Part II. Instructions:**

From your own point of view, please check the appropriate box to indicate how strongly you disagree or agree with the following statement.

1. **Oral or dental health is important for overall health.**

- Strongly disagree**     
  **Disagree**     
  **Indifferent**     
  **Agree**     
  **Strongly agree**

*Thank you for completing this questionnaire, please return it in the envelope that is provided.*