Access to Oral Health Care for Individuals with Developmental Disabilities: An Umbrella Review

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Secretarial Note - please note the *post hoc* addendum to this document, with regard to references to the *Canada Health Act* herein.

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List of abbreviations

AAPD	American Academy of Pediatric Dentistry
AB	Alberta
ASD	Autism spectrum disorder
BC	British Columbia
CDA-ACFD	Canadian Dental Association-Association of Canadian Faculties of Dentistry
CDHA	Canadian Dental Hygienists' Association
CIHI	Canadian Institute for Health Information
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DDS	Doctor of Dental Surgery
DHHS	Department of Health and Human Resources
DSCP	Dental Special Care Program
FASD	Fetal alcohol spectrum disorder
GA	General anesthesia
ETW	Expected-to-Work
ITR	Interim therapeutic restorations
NETW	Not-Expected-to-Work
NU	Nunavut
NWT	Northwest Territories
ODSP	Ontario Disability Support Program
PPMB	Persons with Persistent Multiple Barriers
PWD	Persons with disabilities
SAP	Saskatchewan Assistance Program
RCDC	Royal College of Dentists of Canada
WHO	World Health Organization

Executive summary

Canadians with developmental disabilities often suffer from poor oral health and are faced with many barriers that limit timely access to oral health care. These barriers contribute to poor oral health and associated inequalities. In this umbrella review, we address the state of oral health and oral health care among these individuals, as well as the barriers preventing them from accessing oral health care.

A summary of the key findings are as follows:

1. Individuals with developmental disabilities have poor oral health when compared to non-disabled populations. Poor oral health outcomes can be related to the inability to maintain adequate oral hygiene, as well as difficulty accessing timely oral health care.

2. Oral health care is costly and with the limited availability of public funding in Canada, individuals with developmental disabilities may be left without adequate resources to cover these costs. As a result, these individuals are often left with many unmet oral health treatment needs.

3. The number of hospitals that are equipped with dental departments appears to be insufficient to address the needs of these individuals. This includes access to operating room time for treatment under general anesthesia.

4. There are insufficient numbers of trained oral health care professionals who are able and comfortable to treat the needs of individuals with developmental disabilities. Addressing barriers to providing care by oral health care professionals, such as lack of clinical training and limited reimbursement, is required to increase the available workforce.

5. Undergraduate, postgraduate, or continuing education programs provide insufficient didactic and clinical education regarding oral health care specific to individuals with developmental disabilities.

6. There is very limited regulation and oversight regarding access to timely oral health care for individuals with developmental disabilities, and consonance with the *Canada Health Act* and its specification for surgical-dental services delivered in-hospital may be an issue.

7. There is a need for further research directed towards interventions and/or programs to improve the oral health of individuals with developmental disabilities.

Based on these findings, the following recommendations could be considered to address the disparities in oral health and access to oral health care for individuals with developmental disabilities:

1. Recognition of oral health as an integral component of overall health for all individuals with developmental disabilities.

2. Encouragement of the development of health promotion strategies, geared towards individuals with developmental disabilities and their families and/or caregivers, to increase awareness of the importance of oral health.

3. Re-assessment of the current coverage and availability of publicly funded dental programs for all individuals with developmental disabilities.

4. Exploration of the possibility of increasing the number of functional dental departments located within community hospitals that can provide in-patient and out-patient oral health care.

5. Consideration of options that could improve timely access to operating rooms for dental procedures under general anesthesia for individuals with developmental disabilities.

6. Evaluation of access to care for individuals with developmental disabilities with an eye to the *Canada Health Act* and its specification for surgical-dental services delivered in-hospital.

7. Expanded education for oral health care professionals to address the complexity of oral health care for individuals with developmental disabilities. This could occur in undergraduate, postgraduate and continuing education programs, and would need to involve hands-on clinical training and exposure.

8. Promotion of collaborative and interdisciplinary care between oral health care professionals, other healthcare providers, and personal caregivers who work with individuals with developmental disabilities.

9. Research that will evaluate the effect of different clinical, behavioural and educational interventions on improving the oral health status for individuals with developmental disabilities.

In short, it is clear that inequalities in oral health and access to oral health care exist for individuals with developmental disabilities. The greatest opportunity to improve the oral health of these individuals will lie in the development of effective prevention programs.

1.0 Overview

Individuals with developmental disabilities in Canada may have limited access to oral health care, potentially resulting in poor oral health and quality of life. Understanding their challenges in accessing oral health care is particularly important for policy, given that oral health care plays a significant role in improving health and well-being by alleviating pain and infection, preventing disease, and maintaining masticatory and social function. In this document, we summarize the existing review literature and present findings related to the status of oral health for individuals with developmental disabilities, as well as the barriers that may be limiting their access to oral health care.

2.0 Statement of purpose/background

In 2006, Statistics Canada estimated that there were 4.4 million Canadians living with disabilities[1] that affect daily activities (Statistics Canada, 2012). This prevalence increases with age, with estimates of 10.1% for individuals between 15 and 64 years of age, to 33.2% for seniors 65 and older (Statistics Canada, 2012).[2] As Canada's population continues to grow, and with the life expectancy among children with disabilities increasing, these numbers are expected to increase over the next 20 years (Canadian Dental Association-Association of Canadian Faculties of Dentistry [CDA-ACFD], 2015; Canadian Institute of Health Information [CIHI], 2011).

A subset of this population is individuals with developmental disabilities, which can be affected by a broad range of physical, developmental, cognitive, sensory, and/or behavioural impairments that often require specialized health care services or programs (Crall, 2007). Developmental disabilities may impact mobility, dexterity, hearing, vision, speech and communication skills, chronic conditions, learning, and/or memory in varying degrees (Surabian, 2016; Koneru, 2009). The term 'developmental disabilities' can also include conditions such as intellectual disabilities, communication disorders, cerebral palsy, autism spectrum disorder (ASD), fetal alcohol spectrum disorder, attention-deficit/hyperactivity disorder, specific learning disorder (FASD), motor disorders and/or sensory deficits. Despite having more complex health needs, individuals with developmental disabilities are less likely than the general population to utilize health care services and thus experience poorer health (Hwang et al., 2009; Krahn & Drum, 2007).

The same can be said for oral health, which is an integral component to general health, well-being, and quality of life (World Health Organization [WHO], 2003). It is well documented that individuals with developmental disabilities experience a greater burden of oral disease and a higher unmet need for dental care when compared to those without any disabilities (Glassman & Subar, 2009; CDA-ACFD, 2015). Many people with disabilities also struggle to access dental services (Rush, 2013). Providing dental care for this population requires knowledge and adaptive

[1] For the purpose of this report, persons with disabilities are defined as those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html

[2] This may not be relevant to developmental disabilities in which onset is in the developmental period, typically early childhood.

measures that may go beyond what is considered routine, as physical or cognitive barriers can limit care in traditional settings (Crall, 2007; Canadian Dental Association [CDA], 2010). There are also many environmental, procedural, and financial barriers that can limit their access to necessary oral health care.

Ultimately, while summary literature exists in this area, there is currently no accessible and usable document that compiles evidence from the multiple reviews. Therefore, the purpose of the umbrella review is to summarize and synthesize the existing review literature on the oral health status and access to oral health care of individuals with developmental disabilities, and to provide recommendations for best practice and future research.

3.0 Methodology

The Joanna Briggs Institute Methodology for Umbrella Reviews was adapted for this review (Aromataris et al., 2014). Publications included in this report were based on the inclusion criteria outlined in Table 1.

Table 1. Inclusion criteria.

Element	Criteria
Population	Individuals of any age with any form of: - Developmental disability, or those that cause functional limitations in three or more areas of life such as self-care, receptive and expressive language, learning, mobility, capacity for independent living, and economic self-sufficiency. - Intellectual disability, or a subset of persons who have developmental disabilities, defined as impaired cognitive functioning with onset during the developmental period from birth to age 22.
Interventions/ Programs	Limited to activities related to: oral health promotion; oral health education; oral health care service delivery; oral health disease prevention.
Outcomes	Prevalence, distribution and severity of clinical outcomes; prevalence, distribution and severity of self-reported outcomes; access to oral health care; financing of oral health care; delivery of oral health care.
Sources	Synthesis and systematic reviews; literature reviews; government reports; non-government reports; limited to those written in the English language; Primary studies were excluded.

3.1 Search strategy

An electronic search for available publications from 1980 onwards was conducted using the following electronic databases: Pubmed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), JBI Database of Systematic Reviews and Implementation Reports, the Cochrane Database of Systematic Reviews, and Scopus. We also conducted a search of the grey literature using Google® Scholar and relevant websites for international government documents,

policy statements and guidelines, non-government organization reports, dissertations, technical reports, conference papers and working reports. This was followed by a secondary search of the references cited in the included studies. After relevant publications were identified, abstracts were reviewed to determine if they met inclusion criteria. The list of terms used for electronic database searches is presented in Table 2.

Table 2. Terms used for electronic database searches.

Topic	Search Terms
Population	Developmental disabilities, intellectual disabilities, learning disabilities, mental retardation, cognitive impairment, Down's syndrome, autism, autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), and cerebral palsy
Facilities	Hospitals, Disabilities Act, wheelchair access, and accessibility
Services	Dentistry, dental hygiene, general anesthesia, sedation, special needs dentistry, and prevention
Workforce	Dentists, dental hygienists, pediatric dentists, caregivers, personal support workers, and therapists
Outcomes	Delivery of healthcare, quality of life, quality of care, dental caries, root caries, plaque, periodontal disease, trauma, access to care, and oral health policy

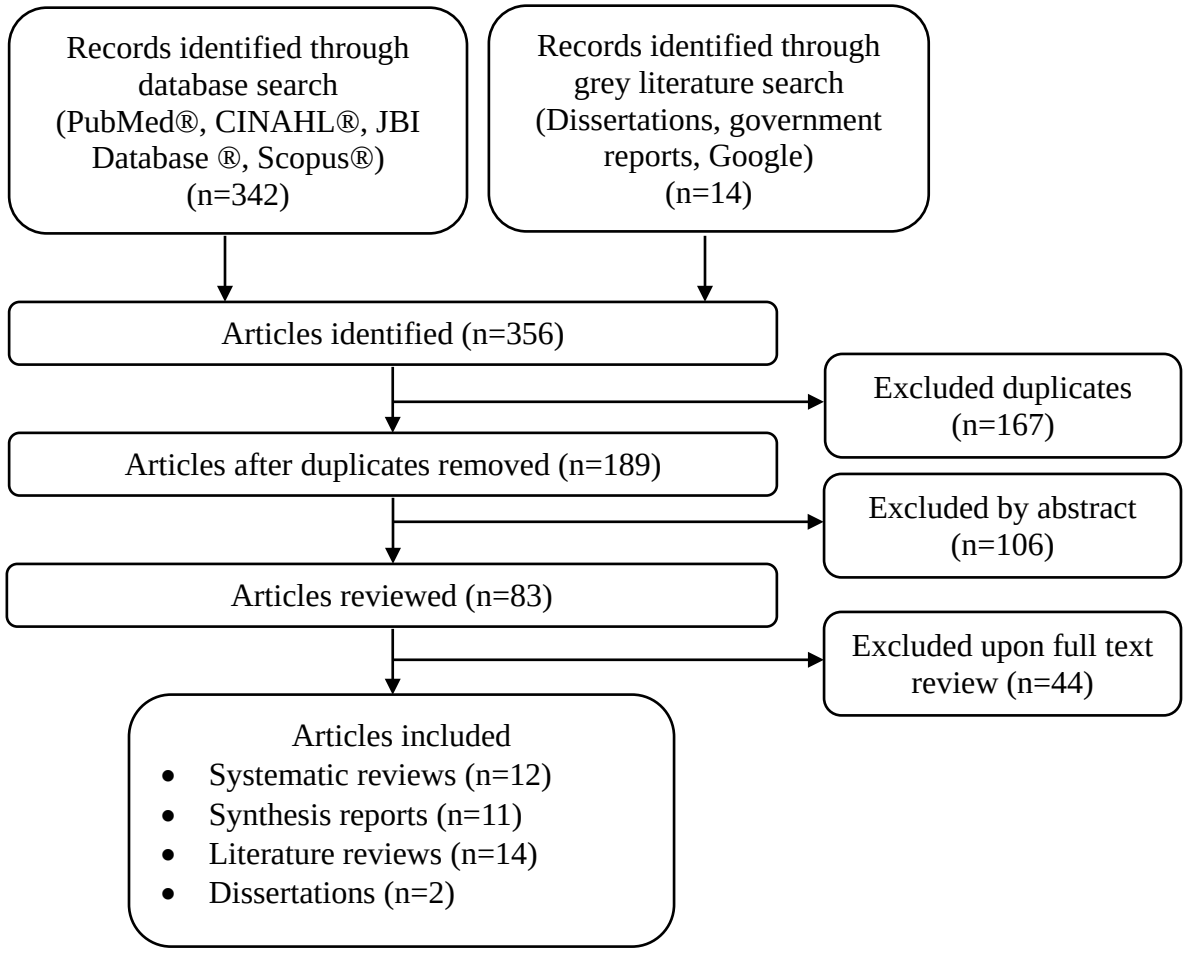
4.0 Findings

The findings of the umbrella review are presented in five sections. A summary of the search results is presented in the first section. The second section describes the financing, related workforce, and delivery of oral health care services for individuals with developmental disabilities in Canada. The third section presents findings related to their current oral health status. The fourth section summarizes possible barriers related to accessing oral health care. Finally, the last section presents an overview of different evidence-based interventions for improving oral health outcomes for individuals with developmental disabilities.

4.1 Search results

The initial search identified 342 potentially relevant publications: 185 from PubMed®, 42 from CINAHL®, 12 from the JBI database®, 89 from Scopus® and 14 from Google Scholar®. Figure 1 shows the results of the consecutive screening and selection of the publications. 83 articles remained for evaluation once duplicates were removed and abstracts screened. After these publications were read in full text, 39 met the inclusion criteria and were ultimately reviewed in this document.

Figure 1. Search and retrieval process flow chart



4.2 Individuals with developmental disabilities and the provision of oral health care

4.2.1 Financing

Basic oral health care is not covered under the *Canada Health Act*. It is predominately financed through private insurance or out-of-pocket payments with public funding representing about 6% of total dental expenditure (Ramraj et al., 2014). As highlighted in Table 3, with the exception of Quebec, the Yukon Territory, The Northwest Territories, and Nunavut, most Provinces have specific public programs that provide funding to cover the cost of oral health care for individuals with developmental disabilities. However, these funding levels are not always in alignment with Provincial dental fee schedules and there are limitations placed on the types of oral health services and amount of coverage available (Shaw & Farmer, 2015; CDA-ACFD, 2015). Most of these plans provide very little funding for sedation and general anesthesia services, which many of these patients require. Furthermore, and of relevance to this population, while there are no provisions for basic oral health care under the *Canada Health Act*, general anesthesia services in

a hospital setting may be covered in part or in whole by Provincial health care plans (Rush, 2013).

4.2.2 Delivery

Dental care for individuals with developmental disabilities can be provided in a number of locations. The first and most obvious is in private dental offices. A summary of dental providers in this context and their corresponding educational requirements is presented in Table 4. Pediatric dentists receive additional training in managing children with developmental disabilities and are often primarily responsible for their dental care. Many will continue to see these patients into their adult years when there are no suitable options for transitioning care. However, with less than 300 active pediatric dentists practicing throughout Canada, there is clearly a shortage of a specialized workforce to manage this population (The Royal College of Dentists of Canada [RCDC], 2016).

Dental anesthesiologists may provide treatment to patients with developmental disabilities as well, particularly when sedation or general anesthesia services are required. These residency programs typically have increased exposure to the management of patients with developmental disabilities. However, there are no additional clinical dental treatment competencies, compared to those obtained through a traditional undergraduate dental school program. Currently, Ontario is the only jurisdiction that recognizes dental anesthesiology as a licensed speciality (RCDC, 2016). General dentists who have sought further training and/or continuing education in sedation can also provide care in their offices for these individuals. Some can do so independently, and others may enlist the aid of a dental or medical anesthesiologist when sedation is required. A select few may have adapted their clinics with specialized lifts or equipment to reduce physical barriers; however, these types of facilities are very rare. Dental hygienists may provide care for individuals with developmental disabilities with no additional training requirements and, in Alberta, British Columbia, the Northwest Territories and Nunavut, dental hygienists may provide treatment using nitrous oxide/conscious sedation if additional training requirements are met; however, this should exclude those patients who are medically compromised (Canadian Dental Hygienists Association [CDHA], 2013).

Select hospitals in Canada may also be equipped with dental facilities and departments that provide care for this group, but these are often limited to major metropolitan cities (Rush, 2013). Treatment in hospital settings can involve routine preventative care and maintenance. However, due to a high demand and extensive waitlists for services, patients are often limited to receiving emergency care or full treatment in the operating room, and then referred back to the community for continuing care. It has been emphasized that there is a great need for more operating-room time to address the problem of lack of timely access to dental treatment for individuals with developmental disabilities (Rush, 2013)

Dental care for individuals with developmental disabilities demands an interdisciplinary approach (Crall, 2007; CDA, 2010). Not only does patient care require a team effort by the dentist, dental hygienist, and dental assistant, but they must also frequently collaborate with primary health care or other health care providers, family members, and social service agencies to facilitate therapy and home care (Koneru, 2009; CDA-ACFD, 2015). Family members and

personal support workers play a particularly important role as they are often primarily responsible for the maintenance of daily oral hygiene and facilitating access to professional oral health care services.

Table 3. Provincial and Territorial public dental program coverage for persons with disabilities.[1]

Province/ Territory	Program	Eligibility criteria for persons with disability	Services Covered	Service Environments
British Columbia	Dental Supplements	- Persons with Disabilities (PWD) $1000/2yrs; - Persons with Persistent Multiple Barriers (PPMB) $1000/2yrs; - Person >65yrs who have retained eligibility for health supplements $1000/2yrs; - Spouses of PWD and PPMB $1000/2yrs; - Children <19yrs who are dependent on client of income or disability assistance and recipients of Children in the Home of a Relative assistance $1400/2yrs. *Levels of benefit depend on income assistance designation	Basic: diagnostic, preventive, restorative, endodontic, periodontal, prosthodontic, oral surgery Orthodontic services (extra)	Dentist and denturist private practices Pays for some treatment performed under GA care in-hospital
Alberta	Alberta Works Income Supports	- Adults who are Not Expected-to-Work (NETW) because of a chronic mental or physical health problem or because of Multiple Barriers to employment; - Adults Expected-to-Work (ETW) who are looking for Work, working or unable to Work in the short term. * Level of benefits depends on income and assets	Standard (ETW): limited to relief from dental pain and oral infection; coverage can include some diagnostic, restorative, and prosthodontic care Supplementary (NETW): includes Standard Benefits with some diagnostic, restorative, endodontic, periodontal, prosthodontic, and oral surgery services	Dentist and denturist/ Private practices

Table 3. Provincial and Territorial public dental program coverage for persons with disabilities.[1]

Province/ Territory	Program	Eligibility criteria for persons with disability	Services Covered	Service Environments
Alberta	Assured Income for the Severely Handicapped	- Adults 18-64yrs with a permanent disability that that severely impairs their ability to earn a living. *Level of benefits depends on income and assets	Supplementary dental coverage as defined above	Dentist and denturist/ Private practices
	Family Support for Children with Disabilities	- Must not be covered under any other plan; - Must be directly related to the child's disability; - Pays for the portion of costs exceeding those covered by the guardian's dental insurance or benefit plan, or if the guardian does not have such insurance, the costs exceeding $250 annually	Supplementary dental coverage as defined above and some orthodontic treatment	Dentist and denturist/ Private practices
Saskatchewan	Supplementary Health Program	- Adults enrolled in Saskatchewan Assured Income for Disability or Saskatchewan Assistance Program (SAP) and their dependents '- Adults >65 years who are in special care homes or hospitals and whose income meets SAP levels	Services limited to relieving pain and controlling infection. For children, full range of basic dental services available.	Dentists, dental therapists/private practice
Manitoba	Health Services - Dental Program	- Includes persons with disabilities	Basic diagnostic, preventive, restorative, endodontic, periodontal, prosthodontic, oral surgery services	Dentists and denturists/private practices, hospitals

Table 3. Provincial and Territorial public dental program coverage for persons with disabilities.[1]

Province/ Territory	Program	Eligibility criteria for persons with disability	Services Covered	Service Environments
Ontario	Ontario Disability Support Program (ODSP)	- Disabled recipient, spouse and dependent children who are in receipt of ODSP income support Additional services are available under the Dental Special Care Plan (DSCP) to eligible recipients whose dental needs result from their disability	Basic diagnostic, preventive, restorative, endodontic, periodontal, prosthodontic and oral surgery services DSCP provides more frequent services such as recall exams, scaling/root planning and additional services such as bruxism appliances and grafts	Dentists/ private practices, hospitals
	Assistance for Severely Disabled Children	- Must be <18yrs living at home with a parent/legal guardian; - Family income is evaluated to qualify - Child must have a severe disability' - Extraordinary costs must be present which are incurred due to disability'	Basic diagnostic, preventive, restorative, endodontic, periodontal, prosthodontic and oral surgery services DSCP provides more frequent services such as recall exams, scaling/root planning and additional services such as bruxism appliances and grafts	Dentists/ private practices, hospitals
Quebec [2]	No information available.			

Table 3. Provincial and Territorial public dental program coverage for persons with disabilities.[1]

Province/ Territory	Program	Eligibility criteria for persons with disability	Services Covered	Service Environments
New Brunswick	Health Services Dental Program	- Adults >19 years with coverage for specific dental benefits that are not covered by other agencies or private health insurance plans. - Individuals who have special health needs and who qualify for assisted health care under Section 4.4 of the Family Income Security Act and Regulations. Additional benefit-specific eligibility criteria may apply. This program is only available to clients who have no other dental coverage.	Basic examinations, x-rays, dentures and repairs, and specific types of fillings. Clients are eligible for a maximum of $1,000 per year, excluding emergency and prosthetic services. Additional fees may apply.	Dentist and denturists/private practices
Nova Scotia	Services For Persons with Disabilities	- Based on an assessment of financial need	Emergency dental care, some diagnostic, preventive, restorative, prosthodontic, endodontic, and oral surgical services Assistance pays 80% to 100% - Based on an assessment of financial need	Dentist and Denturist; private plan
	Mentally Challenged Program	- Anyone deemed mentally challenged by a medical authority, and whose dental needs may necessitate hospitalization	Various oral surgical and dental procedures beyond he eligibility under the Children's Oral Health Program Additional fees may apply.	Specialists and generalists/ hospitals and private practices

Table 3. Provincial and Territorial public dental program coverage for persons with disabilities.[1]

Province/ Territory	Program	Eligibility criteria for persons with disability	Services Covered	Service Environments
Prince Edward Island [2]	Paediatric Dental Specialist Services Program	- Children without a private dental insurance plan who have medical and/or behavioural problems, which require that a paediatric dental specialist treated them	In-hospital provision of children's dental care program covered services.	Paediatric dental specialist
	Social Assistance Dental Services Program	- Adults recipients on assistance - Those deemed physically or mentally challenged	- Emergency dental care to eliminate pain/infection - Removable prosthodontics* - Diagnostic, preventative, and treatment services *Additional fees may apply.	Dentists in private offices
Newfoundland and Labrador [2]	Adults Dental Program	- Includes adults with disability	Basic diagnostic, preventive, restorative, endodontic, periodontal, prosthodontic and oral surgery services. Dentures limited to standard dentures every eight years.	Dentists in private offices
Nunavut	No information available.			
Northwest Territories	No information available.			
Yukon Territory	No information available.			

[1] Information retrieved from Shaw, J.L., Farmer, J.W. (2015). An environmental scan of publicly financed dental care in Canada. Office of the Chief Dental Officer, Public Health Agency of Canada.
[2] Province has universal program for children. Age of coverage varies.

Table 4. Summary of oral health providers and associated training for treating individuals with developmental disabilities, within their respective scopes of practice.

Provider	Number of years in training	Recognized Specialty	Provide comprehensive care using in-office sedation	Provide comprehensive care in a hospital setting	Source
General dentist	DDS program = 4 years General practice residency = 1-2 years	No	Additional training required	Additional training required	CDA-ACFD, 2015
Pediatric dentist	DDS program = 4 years Specialty residency = 2-3 years	Yes	Yes	Yes	RCDC, 2016
Dental anesthesiologist	DDS program = 4 years Specialty residency = 2-3 years	Ontario only	Yes	Yes	RCDC, 2016
Dental hygienists	Degree program = 4 years Diploma program = 2 years	N/A	Conscious sedation with additional training in AB, BC, NWT, and NU	No	CDHA, 2013

4.3 Burden of disease

The oral health needs of individuals with developmental disabilities are complex, and may be related to congenital anomalies, associated co-morbidities, as well as an inability to receive timely personal and professional care to maintain oral health (Anders & Davis, 2010; Weiss, 2014; Popova, 2016). Oral health related problems are rated among the top secondary issues that affect individuals with disabilities that can cause limitations to their daily lives (Owens et al., 2006). In the United Sates, the Surgeon General's Report on Oral Health revealed that no national studies have been conducted to determine the normative prevalence of oral diseases among individuals with disabilities (Crall, 2007; Department of Health and Human Services [DHHS], 2000); however, efforts have been made to assess perceptions of oral health among caregivers of children with disabilities (Kopycka-Kedzierawski, 2008). Consequently, the knowledge base concerning the clinical oral health status of these individuals is incomplete. A summary of relevant findings regarding oral health status is presented in Table 5 and detailed in the following sections.

4.3.1 Oral hygiene

Individuals with developmental disabilities generally have a higher prevalence of poor oral hygiene when compared to the general population (Crall, 2007). In their systematic review, Anders and Davis (2010) report that 25 out of the 27 studies reviewed demonstrated that individuals with intellectual disabilities had poorer oral hygiene. The remaining two studies found no significant difference in hygiene levels. Poor oral hygiene was also correlated with several factors including a younger age, type of primary oral hygiene caregiver (trained versus untrained), and the type of disability (Anders & Davis, 2010). Da Silva et al. (2016) report that children and young individuals with autism or ASD in Brazil present with worse oral hygiene levels, confirmed by the presence of visible plaque or higher plaque indexes during examination. Difficulties with oral hygiene for this subgroup were explained by reduced manual dexterity, the noncompliance of individuals or caregivers, and aversion or sensory hypersensitivity around the oral cavity (Da Silva et al., 2016).

4.3.2 Dental caries

Reported prevalence and incidence of dental caries vary widely and can differ greatly depending on the subtype of developmental disability being studied. Previous studies that examined the dental needs of individuals with developmental disabilities noted the incidence of caries to be similar to non-disabled populations; however, they frequently had higher rates of untreated caries and greater numbers of extracted teeth (Koneru, 2009; Crall, 2007).

Owens et al. (2006) found that anywhere between 18-84% of children and adults with intellectual disabilities have untreated dental caries compared with 16-55% in the general population. Anders and Davis (2010) report that most studies examining the prevalence of dental caries concluded that the rates in individuals with intellectual disabilities were either the same as the non-disabled population or lower. However, while the prevalence of caries was not higher, there were consistently greater levels of untreated caries and missing teeth. Owens et al. (2006) also report that individuals with intellectual disabilities were more likely to receive less

conservative treatment options for dental caries, such as tooth extractions rather than restorations, compared with individuals in the general population.

Table 5. Summary of findings related to oral health outcomes for individuals with developmental disabilities.

Population	Outcome	Indicator	Finding (95% CI)[1]	Source(s)
Developmental Disabilities	Oral hygiene status	Poor oral hygiene	Prevalence = 45.1%	Owens, 2006
Intellectual Disabilities	Dental caries	Caries experience	Prevalence the same as or lower than the general population	Anders, 2010
		Untreated dental caries	Prevalence = 18 to 84% vs. 16 to 55% (general population) Higher incidence rates than general population	Owens, 2006 Anders, 2010
	Periodontal status	unspecified	Higher prevalence and greater severity of periodontal disease vs. general population	Anders, 2010
Individuals with Downs Syndrome	Dental caries	unspecified	Insufficient evidence to show that caries rates are lower than in non-syndromic individuals	Moreira, 2016
Individuals with Mental Retardation	Periodontal status	Gingivitis, Periodontal disease	Higher prevalence vs. general population	Crall, 2007
Children with special health care needs[2]	Oral health status	Poor oral health	Prevalence = 12 to 23%	Crall, 2007
Children with Down Syndrome	Oral health status	Poor oral hygiene	Higher prevalence vs. healthy population	Diéguez-Pérez, 2016
	Habits	Bruxism	Higher prevalence vs. healthy population	Diéguez-Pérez, 2016
Children and young adults	Oral health status	Plaque index scores	Higher prevalence vs. healthy population	Da Silva, 2016

Table 5. Summary of findings related to oral health outcomes for individuals with developmental disabilities.

Population	Outcome	Indicator	Finding (95% CI)[1]	Source(s)
with Autism/ASD	Dental caries	Caries experience	Pooled Prevalence = 60.6% (44.0 – 75.1)	Da Silva, 2016
	Periodontal status	Gingivitis	Pooled Prevalence = 69.4% (47.6 – 85.0)	Da Silva, 2016
Children with ASD and sensory disorders	Dental caries	Dental caries	No difference in prevalence vs. healthy population	Bartolomé-Villar, 2016
	Periodontal status	Gingivitis	Prevalence = 38.2% Higher prevalence vs. healthy population	Bartolomé-Villar, 2016
	Habits	Bruxism	Higher prevalence vs. healthy population	Bartolomé-Villar, 2016
Children with Cerebral Palsy	Oral hygiene status	Poor oral hygiene	Worse vs. healthy population	Diéguez-Pérez, 2016.
	Dental caries	unspecified	Higher prevalence vs. healthy population	Diéguez-Pérez, 2016.
	Dental trauma	unspecified	Higher prevalence vs. healthy population	Diéguez-Pérez, 2016.
Children with sensory disorders	Dental trauma	Fracture in anterior teeth	Prevalence = 32.5% (visual disability) vs. 9.6% (healthy children)	Bartolomé-Villar, 2016
Children with FASD	Dental development	Facial/dental anomalies	May present with micrognathia, cleft lip and/or palate, and small teeth with defective enamel.	Asa, 2010; Itthagarun, 2007

[1] Confidence Interval (CI)

[2] Includes children with speech disorders, behaviour disorders, intellectual disabilities, developmental/physical disabilities, autism, hearing/vision impairments, musculoskeletal problems, depression or anxiety, attention deficit disorder.

For children and young adults with autism or autism spectrum disorder, Da Silva et al. (2016) reported a pooled prevalence of dental caries of 60.6% (95% CI: 44.0–75.1); however, there is limited data regarding the severity of caries. In a systematic review by Bartolomé-Villar et al. (2016), no significant differences were noted in the prevalence of dental caries for children with autism or sensory related disabilities when compared to healthy control groups. When examining individuals with Down Syndrome, where caries prevalence is believed to be lower than non-syndromic individuals, Moreira et al. (2016) concluded that there was insufficient evidence to support this claim. There is also evidence supporting the idea that children with cerebral palsy may have higher prevalence rates of caries when compared to healthy controls (Diéguez-Pérez et al., 2016).

4.3.3 Periodontal disease

Individuals with intellectual disabilities experience a higher prevalence of gingivitis and other periodontal diseases when compared to the healthy population (Crall, 2007). The evidence also suggests that people with intellectual disabilities have a higher prevalence and greater severity of periodontal disease (Anders & Davis, 2010).

Periodontal disease also affects people with Down syndrome, with gingivitis and periodontitis beginning early and increasing in severity with age (Fisher, 2004). Anders and Davies (2010) found that people with Down syndrome and intellectual disabilities have a greater severity of periodontal disease. This was supported by Diéguez-Pérez et al. (2016) who also report that the overall gingival health is worse in individuals with Down syndrome when compared to non-syndromic individuals.

When examining children and young adults with autism or autism spectrum disorder, Da Silva et al. (2016) report that the pooled prevalence for periodontal disease in this group was 69.4% (95% CI: 47.6–85.0). Bartolomé-Villar et al. (2016) also report that children with autism have more or worse gingival/periodontal state when compared to healthy pediatric patients.

Individuals who are unable to meet their nutritional needs orally and who require gastrostomy tube feedings are at significantly increased risk of poor oral health, particularly a build-up of calculus and subsequent gingivitis and periodontitis (Norwood & Slayton, 2013) This increase in calculus results in inflammation due to the lack of normal clearance of the oral cavity that takes place when food is normally chewed (Norwood & Slayton, 2013).

4.3.4 Trauma

While dental trauma is generally considered to be more prevalent in individuals with developmental disabilities, there are very limited studies available looking at this outcome. Yet recent systematic reviews provide evidence that children with cerebral palsy (Diéguez-Pérez et al., 2016) and sensory disabilities (32.5% compared to 9.6% in the healthy population) have a higher prevalence of dental trauma (Bartolomé-Villar et al., 2016).

4.4 Factors related to accessing oral health care

4.4.1 Regulation

Individuals with developmental disabilities have historically been victims of discrimination and isolation from the general population (Rush, 2013). They were traditionally regarded with fear, ignorance, and hopelessness, and kept away in family homes or institutions (Koneru, 2009). At the federal level, the *Canadian Human Rights Act*, passed in 1985, intended to protect all people against discrimination by institutions such as Crown corporations, banks, airlines, television and radio stations, inter-Provincial communications and telephone companies, and railways (McColl et al., 2010). However, it does not apply to hospitals, schools, or similar non-federally regulated organizations, as these institutions are governed by comparable anti-discrimination legislation at the Provincial and Territorial level (McColl et al., 2010).

Legislation also exists, such as *The Accessibility for Ontarians with Disabilities Act*, which is focused on developing mandatory accessibility standards to remove and prevent barriers for people with disabilities in targeted areas of daily living (McColl et al., 2013). This legislation often only addresses physical barriers to daily living and function within society, and does not consider the many other potential barriers, particularly those limiting access to oral health care (Rush, 2013). In her legal analysis in 2013, Rush argues that individuals with developmental disabilities have the legal rights to receive necessary dental treatment in a reasonable time and concludes that government's failure to ensure this is a breach of their basic human rights and a breach of the government's duty of care (Rush, 2013). Consequently, the author concludes that the inability of the government to provide timely access to dental care could potentially leave it vulnerable to legal action (Rush, 2013). Currently, only five Provinces in Canada, (Alberta, New Brunswick, Nova Scotia, Ontario, and Prince Edward Island) have specific legislation mandating dental coverage for individuals with developmental disabilities (Table 6). However, this only addresses the cost of dental care as a barrier and does not consider the many other potential factors that may be limiting access to oral health care.

Another regulatory consideration that has largely remained unexplored in the context of individuals with development disabilities is the issue of compliance under the *Canada Health Act* and associated Provincial/Territorial statutes (Rush, 2013), given the established medical need for hospital-based dental care in this population, and the consistent finding among researchers and policy advocates that this need is inadequately met.

4.4.2 Facilities

The absence of elevators, lifts and ramps to gain entrance to dental offices can be physical barriers to accessing care. Private dental offices can be equipped to treat individuals with developmental disabilities with only minor modifications and so the lack of facilities for the management of such patients is more of a misconception by dentists (Koneru, 2009). However, transportation and proximity related factors can present much greater challenges to accessing dental care (Koneru, 2009). When individuals with disabilities find a dental professional who is willing and able to provide care, the location may not be convenient making it difficult to obtain the necessary transportation. This is a greater concern for those who live outside of major urban

centers (CDA-ACFD, 2015). Access to transportation is a critical shortcoming since 14% of adults with disabilities, representing just over 200,000 people, had difficulty using public transportation or travelling short distances (Human Resources and Skills Development [HRSD], 2009). These individuals must depend on others to transport them to their appointments, or possibly taxi services, representing an additional cost (Koneru, 2009).

Table 6. Summary of legislation specific to oral health care for individuals with developmental disabilities.[1]

Province/ Territory	Statutes and Regulations	Intended Beneficiaries	Relevant Provisions	Notes
British Columbia	No specific legislation			
Alberta	Assured Income for the Severely Handicapped Act, S.A. 2006, c.A-45.1	Persons who satisfy the definition of "severe handicap" (s.1(i)) and otherwise meet the eligibility criteria	Health benefits (the Alberta Adult Health Benefit) are provided to AISH recipients and their dependents or partners (s.3(1)(b)) where they are not ineligible for any reason (s.3(3) and (4))	Minister of Human Services
			The LGIC may make regulations in respect of this Act (s.12)	
	Family Support for Children with Disabilities Act, S.A. 2003, c.F-5.3	Children (under the age of 18 years) (s.1(d)) who have disabilities (s.(1)(c)) and who are not excluded by reasons of ineligibility (s.4.1)	The Minister may make regulations regarding the operation of this Act (s.10)	Minister of Human Services
	Family Support for Children with Disabilities Regulation, Alta. Reg. 140/2004	As above	The costs of dental and orthodontic treatment may be covered if it is recommended by the dental review committee established by the Alberta Dental Service Corporation and are directly related to the child's disability (s.4(1)(j))	Minister of Human Services
			Financial assistance is restricted to either the portion of costs exceeding the costs covered by the guardian's dental insurance or benefit plan, or, if the guardian does not have dental insurance or a benefit plan for dental care, the costs exceeding $250 annually (s.4(1)(j)(A) and (B))	

Table 6. Summary of legislation specific to oral health care for individuals with developmental disabilities.[1]

Province/ Territory	Statutes and Regulations	Intended Beneficiaries	Relevant Provisions	Notes
Saskatchewan	No specific legislation			
Manitoba	No specific legislation			
Ontario	Ontario Disability Support Program Act, 1997, S.O. 1997, c. 25, Sch. B	Eligible persons with disabilities and his or her dependents (s.3)	The person must satisfy the eligibility requirements (s.5 and regulations)	Minister of Community and Social Services
			The LGIC and Minister may make regulations for the operation of this Act (s.55(1) 2)	LGIC may make regulations respecting benefits for ODSP benefit unit members.
	Assistance for children with severe disabilities, O. Reg. 224/98	Children (under the age of 18) and their parents	If financial assistance is paid on behalf of a child, then most of the benefits, including dental, are to be paid if the Director considers them necessary for the welfare of the child (s.7)	Minister of Community and Social Services
				Eligible for the same dental services as children on ODSP

Table 6. Summary of legislation specific to oral health care for individuals with developmental disabilities.[1]

Province/ Territory	Statutes and Regulations	Intended Beneficiaries	Relevant Provisions	Notes
Québec	No specific legislation			
New Brunswick	General Regulation, NB Reg 95-61	Recipients of assistance, including their dependents, as well as those meeting the definitions of blind, deaf and disabled (s.1 and s 16)	Detailed eligibility provisions (s.4)	Minister of Social Development
	Under the Family Income Security Act (O.C. 95-470)		Items of special need include the purchase of health and medical supplies and services that are not covered under the *Health Services Act* and its regulations (s.19(2))	
			The Minister may grant assistance by way of providing a Health Services Card under the Health Services Act (s.23). The system will automatically extend the Health Card every 6 months if case is still active. Requests for a health card from those who are not eligible for assistance must be assessed under Section 4(4). Health cards issued under this section will be approved for a period of 12 months, unless circumstances require a shorter duration	
Nova Scotia	Employment Support and Income Assistance Regulations, N.S. Reg. 25/2001	Persons in need (s.3(g))	Special needs include dental care (s.2(ab)(i)(A))	Minister of Community Services

Table 6. Summary of legislation specific to oral health care for individuals with developmental disabilities.[1]

Province/ Territory	Statutes and Regulations	Intended Beneficiaries	Relevant Provisions	Notes
Nova Scotia	Employment Support and Income Assistance Regulations, N.S. Reg. 25/2001	Persons in need (s.3(g))	Applicants or recipients may request assistance for items of special need and must provide the information required to support the request (s.24(1))	
			If the special need item is for the health or medical requirements of the applicant or recipient or his or her spouse or dependent child, a caseworker may request advice as to the item's appropriateness, necessity and effectiveness (s.25)	
			Items of special need are disbursed in accordance with Appendix A, however if there is documentation that determines the item is necessary but its cost exceeds the maximum, a supervisor may provide the higher documented amount (s.27)	
	Children and Family Services Act, S.N.S. 1990, c. 5	Children in care (s.3(1)(f)) or children with special needs (ss.18 and 19)	Parents or guardians who are unable to provide the services required for a child with special needs may receive assistance from an agency or the Minister to meet the special needs of the child, as specified in a written agreement (s.18)	Minister of Community Services
			The Governor in Council may make regulations for the operation of this Act (s.99)	

Table 6. Summary of legislation specific to oral health care for individuals with developmental disabilities.[1]

Province/ Territory	Statutes and Regulations	Intended Beneficiaries	Relevant Provisions	Notes
Prince Edward Island	Social Assistance Act, General Regulations, R.S.P.E.I. Reg. Ch S-43 EC396/03	Persons in receipt of social assistance ("applicant", s.1(d))	Social assistance provides "items of basic need (s.1(1)(m)) and may include "items of special need" (s.1(1)(n))	
			Persons with disabilities are covered under this act (s.1)	
	Rehabilitation of Disabled Persons Act, R.S.P.E.I. 1988, c. R-12	Disabled persons (s.1(b))	The Minister may provide such goods and services as may be considered for the rehabilitation of any disabled person, including by way of grant, loan or otherwise, dental and orthodontic treatment and care and prosthetic supplies (s.2(c) and (d))	Minister of Community Services and Seniors
				Social Assistance Dental Services
Newfoundland and Labrador	No specific legislation			
Nunavut				
Northwest Territories				
Yukon Territory				

[1] Information retrieved from Shaw, J.L., Farmer, J.W. (2015). An environmental scan of publicly financed dental care in Canada. Office of the Chief Dental Officer, Public Health Agency of Canada.

4.4.3 Hospital dentistry

Due to complex medical and behavioural issues, many individuals with developmental disabilities will require dental care in hospital settings. Hospital outpatient dental services can greatly facilitate the management of these individuals (Hulland, 1997). Community hospitals can expedite medical consultation services, provide treatment under general anesthesia, and provide inpatient care when required (Hulland, 1997). However, it has been reported that there are an insufficient number of hospital dental departments across Canada to meet the needs of this population (CDA-ACFD, 2015). This can lead to patients being placed on waitlists often delaying treatment for several years (Rush, 2013). Furthermore, there is a lack of access to operating room time because of the low priority for dental services when compared to other surgical services (Rush, 2013). Other barriers to providing dental care in hospital settings as reported by dentists include: the need for additional post-graduate dental training; lack of organized dental departments; hospital administrative burdens; limited availability of dental equipment; and concern that a willingness to provide care will result in more referrals creating a situation where an individual dentist may have to treat a disproportionate number of patients (Table 7) (CDA-ACFD, 2015).

4.4.4 Individual-level factors

Individuals with developmental disabilities can have complex medical, physical, cognitive, communication, and behavioural issues that may limit their access to dental care (Table 8). Depending on the nature of the disability, these individuals often have predisposing health concerns, such as cardiac abnormalities, multiple medications, immunosuppression, and bleeding disorders that can complicate the provision of dental care (Edelstein, 2007).

In the clinical setting, poor oral health status may be related to difficulties in obtaining accurate diagnoses. These patients may have a limited ability to describe pain or articulate their symptoms (Koneru, 2009). Some individuals with developmental disabilities may not be able to cooperate or be resistant with oral health professionals during examinations, limiting the ability for proper clinical and radiographic assessment, and ultimately proper diagnosis (Koneru, 2009). These individuals may also present with oral complications such as limited mouth opening, oral aversion, deficient swallowing reflex, excessive saliva production, a strong gag reflex, and lingual interference that can limit intra-oral access (Edelstein, 2007; Norwood & Slayton, 2013). Individuals with ASD may also present with sensory issues, particularly an aversion to touch and sound, which can impact their ability to receive oral health care (Bartolomé-Villar et al., 2016).

Individuals with developmental disabilities may also experience high levels of anxiety and fear related to dental procedures and a lack of coping skills to tolerate discomfort and pain (CDA-ACDF, 2015). This can lead to missed or cancelled appointments in order to avoid potentially stressful situations (Koneru, 2009). For individuals with specific intellectual or mental disabilities, difficulty obtaining dental care may also be attributed to the degree of mental functioning (Koneru, 2009). A lack of understanding and comprehension of the disease and subsequent treatment options may also impact the ability to accept and follow through with dental treatment (Edelstein, 2007).

Table 7. Reported barriers to delivering oral health care to individuals with developmental disabilities.

Reporting group	Service	Type of barrier	Findings	Source(s)
Individuals with developmental disabilities	Comprehensive dental care	Facility/ Organizational	• Travel distance/proximity to dental offices • Difficulties with public transportation • Cost of transportation	Koneru, 2009
Dentists	Comprehensive dental care	Competency/ Training	• Lack of exposure/education • Lack of clinical training	Davis, 2009
		Facility/ Organizational	• Increased time for treatment • Low reimbursement • Inadequate facilities and equipment • Difficulty obtaining informed consent • Concerns with staff and provider safety	Davis, 2009; Romer, 2013
		Patient-level	• Absence of legal guardians • Patient anxiety to dental treatment • Hypersensitivity to touch and sound • Social relatedness and communication impairments • Pain associated with an inability to communicate • Sensory and social overload • Increased presence of oral aversion • Limited mouth opening • Complex medical conditions	Koneru, 2009; CDA-ACDF, 2015
Dentists	Hospital Dentistry	Competency/ Training	• Additional training required	CDA-ACDF, 2015

		Facility/ Organizational	• Limited hospital dental departments • Limited equipment/facilities within hospitals • Low priority for dental treatment in hospitals • Hospital administrative burdens • Long waiting lists	CDA-ACDF, 2015; Rush, 2013

4.4.5 Provider-level factors

Availability of dental care for individuals with developmental disabilities can be problematic due to a shortage of dentists and dental hygienists who are willing and/or trained to provide treatment to this group (Davis, 2009). Barriers cited by dentists are summarized in Table 8, which include increased treatment time, poor reimbursement, lack of training and knowledge, and inadequate facilities (Davis, 2009; Koneru, 2009). In Ontario, for example, while the proportion of dentists who report that they are willing to treat these patients is increasing, from 20% in the 1980s up to 89% in more recent surveys, the percentage of those who actually provide treatment may not be as high (Koneru, 2009).

4.4.5.1 Time and reimbursement

In Canada, the fee-for-service reimbursement mechanism for most dental services does not account for additional time that may be required for accommodating patients' behavioural needs. While some dentists have claimed that extra time is needed to treat persons with disabilities, others argue that this is not necessarily the case (Koneru, 2009). Poor or unpredictable patient co-operation and uncontrolled movements can impair quality of care and prolong the time needed to complete treatment (Davis, 2009). To spend an excessive amount of time (perceived or not) to complete necessary treatment may not be economically viable for many dentists working in the private practice model (Davis, 2009).

For those who do provide treatment for individuals with developmental disabilities, the reimbursement by publicly funded dental programs, which many of these patients rely on, is often considerably lower than the fees suggested by Provincial dental associations (CDA-ACFD, 2015), which are the fees generally paid by the significant majority of patients whose oral health care is funded by other means. In some jurisdictions, fee schedules may barely cover a dentist's operational overhead (Davis, 2009). The lack of compensation may result in a reduced incentive for dentists to providing care for these individuals (CDA-ACFD, 2015).

4.4.5.2 Education

Canada does not recognize specialization in special needs dentistry, such as exists in the United Kingdom, Australia, and New Zealand (Rush, 2013). While children with developmental disabilities can be treated by pediatric dentists, there is no comparable specialized provider for adults. Consequently, if children with developmental disabilities grow too large to be seen by pediatric dentists, they are often left with no place to go (Rush, 2013).

Historically, there has been very limited education and training in dentistry for individuals with developmental disabilities (Dougall & Fiske, 2008). Recent dental school graduates often report that their pre-doctoral education was insufficient to prepare them to confidently treat patients with special needs (Davis, 2009). Evidence suggests that graduates' perceptions of competency to treat these individuals relates directly to their lack of dental school experiences (Edelstein, 2005). While the Commission for Dental Accreditation of Canada requires that all dental students have didactic and clinical exposure to patients with developmental disabilities, the nature and extent to which this must be provided is not clear (CDA-ACFD, 2015). In the United

States, the American Dental Association identified that improved access for individuals with developmental disabilities needs to begin in dental schools, which are providing minimal training in caring for these patients (Fisher, 2012). The need for additional faculty trained in dentistry for special needs patients has also been proposed, as were opportunities for improved curriculum and multi-disciplinary training for dental professionals and the associated health care providers that often collaborate in this care (Dolan, 2013). Expansion of pre-doctoral education and increasing the number of post-graduate residency and fellowship programs that emphasize care for individuals with developmental disabilities is imperative in order to prepare the dental workforce to adequately provide comprehensive care for this population.

Aside from oral health care professionals, family members or personal support workers may also benefit from basic oral health education, as they are often primarily responsible for the maintenance of daily hygiene for these individuals. Hands-on demonstrations and the learning of practical oral hygiene techniques could be beneficial, however, no research was found in this area.

4.4.5.3 Legal considerations

Dentists who provide treatment to individuals with developmental disabilities are often faced with unique medical-legal challenges (Romer, 2009). Legal barriers to care often revolve around the issues of informed consent and guardianship. The potential need for immobilization or restraining aides during treatment may further complicate the situation (Romer, 2009). Many dentists may not feel comfortable dealing with the legal and potential human rights associated backlash related to patient-restraint and may choose not to treat these patients for this reason (Koneru, 2009).

Individuals with developmental disabilities have the right to refuse treatment if they are able to process information rationally and comprehend the situation and its consequences (Shuman & Bebeau, 1994). However, obtaining informed consent when a patient does not have the mental capacity to do so can be a lengthy and involved process (Koneru, 2009). Although a person with a developmental disability may not be able to act independently, their need for informed consent is still lawful. Legal guardianship can be difficult to establish, but this is critically important since legal guardians have the final say regarding treatment decisions for disabled persons deemed incompetent by the courts (Koneru, 2009). Individuals with developmental disabilities can be dependent on their family members or legal guardians to make informed decisions regarding their oral health care. An additional barrier to timely dental care can arise when these legal decision makers are not accessible for discussion and to provide consent during dental appointments. It is very common for caregivers or auxiliary personnel who are not authorized to make decisions on behalf of the patients to provide transportation to dental appointments (Koneru, 2009).

4.5 Oral health programs and interventions

Individuals with developmental disabilities may be at increased risk for dental disease and as such could greatly benefit from efforts in risk assessment, prevention, and health promotion (CDA ACDF, 2015). A summary of interventions and best practice guidelines are presented in

Table 8; however, it should be noted that there were very limited systematic reviews available regarding preventive clinical therapies for this population.

For children with special health care needs, the American Academy of Pediatric Dentistry (AAPD) advocates for the establishment of a dental home, or a place where these children can go for routine comprehensive and preventive care (American Academy of Pediatric Dentistry [AAPD], 2016). A recent systematic review by Molina et al. (2011) looked at the effect of different prevention strategies used to manage dental caries in this population. This included studies that explored different combinations of education, preventive and restorative interventions. Owing to the heterogeneity of the studies included in the review, they were unable to extract a common strategy for the prevention and treatment of dental caries in people with disabilities (Molina et al., 2011). The current AAPD (2016) guideline for prevention strategies for individuals with developmental disabilities, which is endorsed by the Canadian Academy of Pediatric Dentistry, is also outlined in Table 8.

When treating individuals with developmental disabilities where circumstances may not permit traditional restorative treatment or when caries control is necessary prior to placement of definitive restorations, Interim Therapeutic Restorations (ITR) may be beneficial (AAPD, 2016). A recent meta-analysis by de Amorim et al. (2012) showed that survival rates for single surface and multi-surface posterior ITR restorations in primary teeth over the first two years were 92.8% and 64.9% respectively. ITR has also been shown to have the greatest success rates when applied to single surface or small two surface restorations and as such are best used for conservative restorations (de Amorim et al., 2012). However, there is still a need for further clinical trials dealing specifically with special needs populations.

Table 8. Suggested oral health interventions for individuals with developmental disabilities.

Population	Intervention	Outcome	Source(s)
Individuals with developmental disabilities	Prevention and treatment strategies	Insufficient evidence to support the use of a common strategy for the prevention and treatment of dental caries	Molina, 2011
Individuals with special health care needs/developmental disabilities	Evidence-based best practice guidelines	i) Oral hygiene education for caregivers ii) Regular supervision/assistance of tailored oral hygiene routine iii) Twice daily brushing with fluoride dentifrice (or a fluoride rinse if there is an aversion for the flavor/texture of toothpaste) iv) Use of motorized toothbrushes or modification of toothbrush handles for those with limited manual dexterity v) Use of dental sealants vi) Professionally applied topical fluorides at regular intervals (as determined by caries risk level) vii) Interim therapeutic restorations (ITR), a minimally invasive restorative technique using fluoride releasing glass ionomers viii) Discuss the potential increased risk of dento-alveolar trauma, and mouth guard fabrication when indicated	AAPD, 2016

5.0 Summary

Individuals with developmental disabilities often suffer from poor oral health and an inability to access timely oral health care. In this review, we addressed the state of oral health care for these individuals, as well as the potential barriers preventing them from accessing oral health care.

There were several limitations to this umbrella review. The use of electronic sources does not capture unpublished data such as results from pilot projects or existing initiatives. This review also did not consider primary studies, therefore was dependent on the existence of quality review literature.

Unfortunately, no proven model to improve access to oral health care for individuals with developmental disabilities exists. The next best approach is to combine the findings in the literature with knowledge of the oral health needs and service gaps in the community to develop recommendations for a comprehensive approach.

In this regard, the key findings regarding the oral health status and potential barriers limiting access to oral health care include:

- Poor oral health: Individuals with developmental disabilities have difficulty maintaining oral hygiene and accessing timely oral health care and thus often experience higher rates of untreated dental caries and periodontal disease.

- Financial barriers: With limited public funding available, many individuals with developmental disabilities, particularly adults, are left without adequate resources to cover the costs of oral health care.

- Reimbursement: Additional treatment time and low reimbursement rates are reported by many oral health care professionals as barriers to providing care for this population.

- Delivery of care: There are insufficient numbers of trained oral health care professionals who are able and comfortable to treat the oral health care needs of individuals with developmental disabilities.

- Hospital Dentistry: There is a lack of hospitals equipped with functional dental departments and limited access to time in operating rooms, resulting in long waiting periods for individuals who need these services.

- Regulation: Legislation exists in some jurisdictions mandating the elimination of physical barriers to accessing facilities. Some jurisdictions also have legislation regarding provisions for funding of oral health care. However, these regulations are often insufficient to overcome the many barriers limiting access to care. Thus, given established medical need for hospital-based dental care, and the consistent finding that this need is inadequately met, the consonance of these barriers with the *Canada Health Act*, and its specification for the delivery of surgical-dental services delivered in-hospital, is uncertain.

- Education gaps: Oral health care providers may not have the necessary training and education required to provide adequate care for individuals with developmental disabilities.

- Knowledge gaps: There are limited high quality studies that evaluate the effect of different interventions to improve the oral health status for individuals with developmental disabilities.

6.0 Recommendations

Based on the evidence presented in this umbrella review, the following recommendations could be considered to address the disparities in oral health and access to oral health care for individuals with developmental disabilities:

1. Recognition of oral health as an integral component of overall health for all individuals with developmental disabilities.

2. Encouragement of the development of health promotion strategies, geared towards individuals with developmental disabilities and their families and/or caregivers, to increase awareness of the importance of oral health.

3. Re-assessment of the current coverage and availability of publicly funded dental programs for all individuals with developmental disabilities.

4. Exploration of the possibility of increasing the number of functional dental departments located within community hospitals that can provide in-patient and out-patient oral health care.

5. Consideration of options that could improve timely access to operating rooms for dental procedures under general anesthesia for individuals with developmental disabilities.

6. Evaluation of access to care for individuals with developmental disabilities with an eye to the *Canada Health Act* and its specification for surgical-dental services delivered in-hospital.

7. Expanded education for oral health care professionals to address the complexity of oral health care for individuals with developmental disabilities. This could occur in undergraduate, postgraduate and continuing education programs, and would need to involve hands-on clinical training and exposure.

8. Promotion of collaborative and interdisciplinary care between oral health care professionals, other healthcare providers, and personal caregivers who work with individuals with developmental disabilities.

9. Research that will evaluate the effect of different clinical, behavioural and educational interventions on improving the oral health status for individuals with developmental disabilities.

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ADDENDUM

24 August 2017

The CHA and Surgical Dental Services – Context:

The *Canada Health Act* (CHA) establishes criteria and conditions related to insured health services that the provinces and territories must fulfill in order to receive the full federal cash contribution under the Canada Health Transfer (CHT). There are two criteria of the Act that are applicable to access to insured surgical-dental services.

The comprehensiveness criterion of the Act states that the health care insurance plan of a province or territory must cover all insured health services. Insured health services are defined under the Act as medically necessary hospital, physician and surgical-dental services performed by a dentist in a hospital, where a hospital is required for the proper performance of the procedure. Therefore, dental services are not considered an insured service.

The intent of the CHA when drafted was to publicly insure the professional component of corrective oral-facial surgery procedures resulting from accident injuries or congenital malformations, and are required to be performed by medical or dental professionals in a hospital. It was also intended to include those instances where the condition of the patient necessitates a hospital, such as in the case of co-morbidities (e.g., transplant patients, certain heart conditions). Provinces were to be left with the scope to decide what procedures require a hospital for proper performance. These decisions are usually based on clinical practice standards set by the health professionals involved and the specific clinical indications of each individual patient, on a case-by-case basis.

The *Canada Health Act Annual Report* (CHAAR) outlines the insured surgical-dental services provided in each jurisdiction. For example:

- In Nova Scotia, surgical-dental services are insured when the condition of the patient is such that it is medically necessary for the procedure to be done in a hospital and the procedure is of a surgical nature.
- New Brunswick's *Medical Services Payment Act* identifies the insured surgical-dental services that can be provided by a qualified dental practitioner in a hospital, providing the condition of the patient requires services to be rendered in a hospital.
- In Saskatchewan, insured surgical-dental services are limited to services in connection with maxillo-facial surgery required as a result of trauma; treatment services for the orthodontic care of cleft palate; extraction of teeth when medically required; surgical treatment for temporomandibular joint dysfunction; dental implants in exceptional circumstances (tumours and congenital) upon request from a specialist in oral maxillofacial surgery and with prior approval from the Medical Services Branch; and certain services in connection with abnormalities of the mouth and surrounding structures.
- In British Columbia, included as insured surgical-dental procedures are those related to remedying a disorder of the oral cavity or a functional component of mastication. Generally this would include oral surgery related to trauma, orthognathic surgery, medically required extractions, and surgical treatment of temporomandibular joint dysfunction.

A copy of the most recent CHAAR can be found here: https://www.canada.ca/en/health-canada/services/publications/health-system-services/canada-health-act-annual-report-2015-2016.html

The intent of the Act's accessibility criterion is to ensure that insured persons in a province or territory have reasonable access to insured hospital, medical and surgical-dental services on uniform terms and conditions, unprecluded or unimpeded, either directly or indirectly, by charges (user charges or extra-billing) or other means (e.g., discrimination on the basis of age, health status or financial circumstances).

Reasonable access in terms of physical availability of medically necessary insured health services has been interpreted under the CHA using the "where and as available" rule. Thus, residents of a province or territory are entitled to have access on uniform terms and conditions to insured health services at the setting "where" the services are provided and "as" the services are available in that setting. As the primary responsibility to organize and deliver health care services to Canadians falls within PT jurisdiction, the federal government cannot direct the PT governments to provide services in a particular way or in a specific geographic region and there is nothing in the CHA that can compel hospitals to offer a particular service. PTs have the authority to make policy decisions about the provision of services according to their own priorities.

Access to Oral Health Care for Individuals with Developmental Disabilities: An Umbrella Review

In terms of the paper that you asked us to review, although there is some reference to delays in relation to surgical-dental procedures, the main focus of the paper and the evidence presented is on dental services that are not captured under the CHA.

Strategic Policy Branch (SPB) / Canada Health Act Division (CHAD) Health Canada / Government of Canada

Direction générale de la politique stratégique (DGPS), Division de la Loi canadienne sur la santé (DLCS) Santé Canada / Gouvernement du Canada