An Exploration of Access to Dental Care for Adults with Developmental Disability

by

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Abstract

Objectives: Dental services for children and adolescents with special health care needs, such as developmental disabilities, are reasonably accessible in tertiary care hospital dental departments and in the private offices of pediatric dentists. However, once these young people become adults, accessing dental care is often problematic. This qualitative study explored the experiences of adults with developmental disabilities (AWDD) accessing dental services in the Lower Mainland of British Columbia

Methods: This research used a qualitative approach. AWDD service organizations and family support groups facilitated recruitment of participants. Time was devoted to engaging and building relationships with participants before beginning the research. The focus groups were guided by open-ended questions, audiotaped and then transcribed. Each focus group lasted, on average, forty minutes. Participants were either "self-advocates" (AWDD who speak or act on behalf of themselves or others on issues that affect people with disabilities) or parents of the more severely compromised AWDDs. Each transcript was coded; the codes were organized into themes and finally into domains.

Results: Five focus groups with twenty participants were conducted; two groups were with AWDDs and three with parents. Seven domains relating to the experiences of AWDD self-advocate and their family members with dental care were identified. These domains were communication, trust, respect, financial issues, transitional services, waiting times and, finally, what makes for a "positive dental experience".

Conclusions: "Provider-based" domains of trust, respect and communication arose as essential to the quality of the dental experience for AWDDs and their parents. The domains of financial issues, wait times and transitional services were "system-based" barriers to access to dental care for theses AWDDs. Acknowledgement of the parent's role as advocates and simple, but thoughtful, accommodations by the dental office positively enhanced the dental experience for AWDDs.

Preface

Identification and design of this research project were by the author under the direction of his research supervisors, Dr. Rosamund Harrison and Dr. Mario Brondani. All aspects of the data collection and the analysis of the data were conducted by the author with the guidance of his supervisory committee. Regular committee meetings were held with the supervisory committee. The committee included the two co-supervisors, Drs. Brondani and Harrison and Ms. Joan Rush, adjunct professor in the Faculty of Dentistry.

The Behavioral Research Ethics Board of UBC gave ethics approval (H12-02838). The online ethics-training module Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE) was issued and completed by the author on December 11, 2011.

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"A teacher is a compass that activates the magnets of curiosity, knowledge and wisdom in the pupils." - Ever Garrison

Dedication

For my Mother and Father.

1.Introduction

1.1 Developmental disability: definition and prevalence

The term "developmental disability" (DD) is one of many terms used to refer to delayed intellectual ability and compromised function [1]. However, the definitions of developmental disability vary greatly. In a broad sense, developmental disability includes the diagnoses of mental retardation as well as other developmental disorders and has also been used interchangeably with the term intellectual disability [1]. In the latest diagnostic and statistical manual of mental disorders (DSM V), developmental disability is defined as *"Deficiencies that effect adaptive functioning in three domains. The conceptual domain (language, reading, writing, math and reasoning), the social domain (empathy, social judgment and interpersonal communication skills) and the practical domain (self-management in personal care, job responsibilities, money management, etc.)"*[2].

One method of integrating different conditions and syndromes under the umbrella term "developmental disability" is to look for a common link. This connection is the executive (or adaptive) functional deficit, which is defined as all skills that enable a person to have intentional, goal-directed and problem solving functionality [3]. Some of the conditions most commonly associated with developmental disability include cerebral palsy, autism, Down syndrome, spina bifida and a variety of genetic syndromes such as Fragile X syndrome [4].

In the province of British Columbia the age of majority is 19 years of age[1]. After this threshold, individuals with developmental disabilities are considered to be adults with developmental disabilities (AWDD) and are no longer eligible for pediatric and adolescent services [5].

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[1] http://www.canadainternational.gc.ca/united_kingdom-royaume_uni/visas/minors-mineurs.aspx?view=d Accessed March 21, 2014

An accurate prevalence of developmental disability in the general population is difficult to determine, due to variability in definitions of the term "developmental disability". Different studies use different inclusion criteria and therefore report different population estimates. The majority of published reports suggest a global prevalence of between 1% and 3% [6]. A 1996 U.S study reported a prevalence of 0.9% or 9.1 per 1000 population [7]. A meta-analysis of all prevalence studies of intellectual disability reported a similar global prevalence of 1.4 per 100 population [6].

The number of people with disabilities is increasing due to overall growth of the Canadian population, the aging of the population and better and earlier diagnosis [8]. The Participation and Activity Limitation Survey (PALS) provides the most recent Canadian statistics on developmental disability. This survey, a post-censal survey that relies on self-reports, used the 2006 Census as a sampling framework. Data was provided by about 22,500 adults, 15 years and older, with disabilities. The survey estimated that 4.4 million Canadians had some form of disability, with 11% of adults reporting some sort of disability with agility, mobility and pain [2]. About 136,570 adults, or 0.5% of the Canadian adult population, were estimated to have had a developmental disability[3].

In 2001, The BC Ministry of Children and Family Development estimated the prevalence of developmental disability (adults and children) in the province to be 1%[4]. Based on the latest population figures for British Columbia, a prevalence of 1% means that about 44,000 people in B.C. live with a developmental disability.

[2] http://www.statcan.gc.ca/pub/89-628-x/2007002/t/4125013-eng.htm Accessed November 26, 2013
[3] http://www.statcan.gc.ca/pub/89-628-x/2007002/t/4125017-eng.htm Accessed November 26, 2013
[4] http://childhealthpolicy.ca/wp-content/themes/chpc/pdf/RR-13-06-full-report.pdf Accessed November 26, 2013

1.2 The evolving AWDD community

1.2.1 Increased life expectancy

One primary reason for the increase in AWDD populations is their enhanced life expectancy. In 1949 the average life expectancy for a child with Down syndrome was 12 years of age [9]; in 2004 the average was nearly 60 years old [10]. In fact, based on these trends, life expectancy for AWDD's with Down syndrome will ultimately approach that of the general population. The major reason for this change have been improved health status of AWDD's, the benefits of community rather than institutional living, and access to proper medical care during childhood [11].

1.2.2 Move to community from institutions

Prior to the 1970's, attitudes towards AWDD by government organizations were quite different than today. AWDD were regarded as needing constant observation and guarding for fear of injury to others or to themselves. Therefore institutions were the preferred mode of residence and of care delivery. In the 1970's there was a transition away from institualization and into community living. Family members, the primary instigators of this transition movement, aspired for a better life for their sons and daughters currently in institutions. The AWDD community then also began to advocate for their rights [12, 13].

The primary legal argument was that AWDD are citizens who have the right to participate in community life and that, with appropriate services and supports, can live and engage in regular activities in their communities [12]. This move towards "de-institualization" has also had an effect on oral health care for the AWDD population. Previously, most of the dental treatments for AWDD were done "in house" with institutional staff dental professionals. Due to de-institutionalization, more AWDD currently live at home or in group-homes and, therefore, are in regular need of community based dental services [14].

Since the move towards de-institualization, a major source of dental care has been

hospital dental facilities. In fact provincial governments are required by law to provide such services[5]. AWDD have the same rights under the Canadian Charter of Rights and the BC human rights code for access to dental care in hospital settings[6]. Therefore major changes in the living situation of AWDD community in the past 20 years have also had a major impact on how the AWDD population receives dental care.

1.3 Access to care

1.3.1 Definition of access to care

Access to care is a multifaceted concept that can be looked at from multiple different perspectives. A simple definition is the situation where there is a sufficient supply of services and a given population has the opportunity to access the services. However the extent to which a population gains access to these services depends on multiple factors. These factors include financial, social, cultural and organizational issues [15]. Therefore if we are to measure access by quantifying the utilization of services, we must not only focus on the "supply side" of the equation, but also look at the potential barriers to gaining access to the service [16].

To enhance understanding of access to health services, a model was proposed by Ronald M Anderson in the 1960's and then updated in the 1990's (Figure 1). This well regarded model proposes three major population characteristics as determinants of access to health care: predisposing characteristics, enabling resources and need factors [17]. Predisposing characteristics are the elements related to the individual that influence care-seeking behavior and include age and health beliefs. Enabling resources are the elements that empower and assist individuals in gaining access to health services, for example family support, availability of finances or insurance. Need factors are understood as both the actual need and the perceived need for health care services [18].

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[5] http://www.parl.gc.ca/content/lop/researchpublications/944-e.htm#4insured Accessed June 27, 2014
[6] http://family.gobaci.com/wp-content/uploads/2013/01/Help-Teeth-Hurt.pdf Accessed November 26, 2013

Figure 1: Anderson's behavioral model of health services use

ENVIRONMENT **POPULATION CHARACTERISTICS** **HEALTH BEHAVIOR** **OUTCOMES**
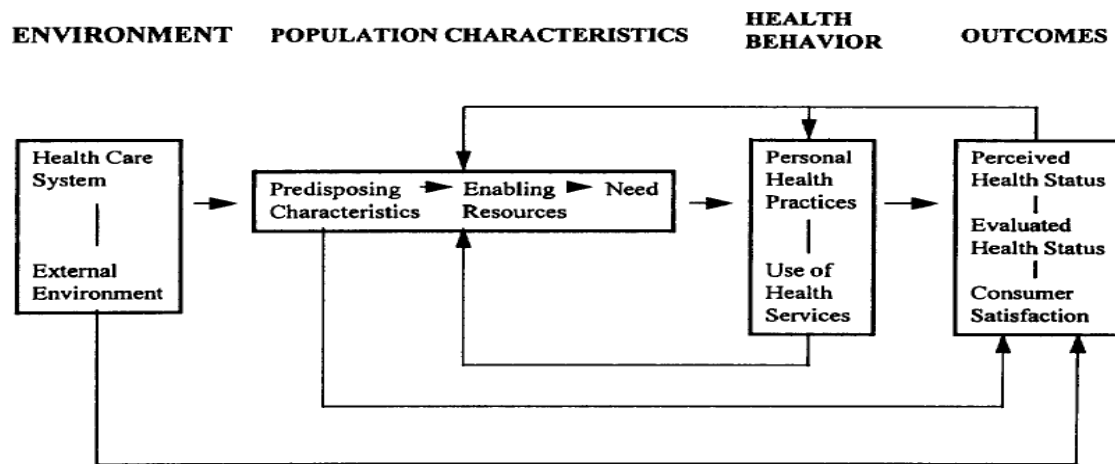
Source: Andersen, R. M. (1995). "Revisiting the behavioral model and access to medical care: does it matter?" J Health Soc Behav **36**(1): 1-10.

Not withstanding these population characteristics influencing health care services utilization, access to such services remains a complex issue. In 1981, Penchansky and Thomas proposed a now commonly used theoretical framework of access to care commonly known as the "5 A's of access" (Figure 2). The core idea behind this framework is to assess access as *" a measure of fit between the characteristics of the provider and health services and characteristics and expectations of the clients" [19].* According to this framework, access is understood within five distinctive domains: affordability, availability, accessibility, accommodation and acceptability, all characteristics of the providers and clients [19].

Table 1: 5 A's of Access

	Definition given by Penchansky and Thomas
Affordability	The relationship between the prices of the services and the clients ability to pay for them
Availability	The relationship of the volume and type of existing services to the client's volume and type of need.
Accessibility	The relationship between the location of the supply of services and the location of the clients.
Accommodation	The relationship between the manner in which the supply of services are organized and the clients ability to accommodate to these factors.
Acceptability	The relationship between the client's perception about the service provider's personal characteristics and service provider's actual characteristics.

Source: Penchansky, R. and J. W. Thomas (1981). "The concept of access: definition and relationship to consumer satisfaction." <u>Med Care</u> **19**(2): 127-140.

This framework allows examination of the importance of each aspect of access to care and enables the development of theories and concepts in regards to possible barriers to care while informing the development of questions aimed at revealing the relevance and magnitude of such barriers [20].

1.3.2 Access to medical care for AWDD in Canada

In 2010, Statistics Canada reported that nearly one in five Canadians experienced difficulty accessing routine or ongoing medical services for themselves or a family member[7]. Previously in 2002, nearly 4.3 million people reported having had some sort of difficulty in accessing care, therefore it can be speculated that about 11% of Canadians likely had unmet healthcare needs [21], mostly a result of:

- Difficulty getting an appointment (42%)

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[7] http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/system-regime/2010-fed-comp-indicat/index-eng.pdf Accessed November 26, 2013

- Long waiting times (33%)
- Long in-office waits (20%)
- Difficulty contacting a physician (13%)

For the AWDD population, such barriers further complicate access to medical care that is already hindered by physicians being ill prepared to treat them, stigma and environmental hurdles including distance to travel and wheelchair accessibility [22]. A survey of AWDD in Ontario demonstrated that while the percentage of visits to family physicians was similar to other adults showed that AWDD patients were more likely to visit the emergency department [23]. AWDD were also less likely to have visited a medical specialist with the exception of neurologist. The authors postulated that the reasons for this disparity could be poor coordination of care between primary care and specialist care, lack of training and education of providers, issues with patient transportation or communication.

The compounding effect of a physical plus a developmental disability increases the difficulties that this segment of the population faces in regards to access to health care in general and dental care in particular [24]. Moreover, life expectancy changes and de-institutionalization efforts have had a noticeable impact on this population.

1.4 The oral health status of AWDD

Results of reports on the oral health status of AWDD are variable. Surveys have identified problems such as poor oral and denture hygiene, gingivitis, bruxism, tooth loss, and an increased number of traumatic injuries to the teeth and mouth [25-27]. Surprisingly, experience of caries in AWDD living in group homes and residential care settings is lower than that of the general population. This finding may be explained by limited access to refined carbohydrates and also by early removal of teeth in need of restoration [28]. Other investigators report that AWDD's have higher plaque levels and poorer oral hygiene than the general population [29]. A 2012 U.S study demonstrated a higher burden of dental disease for AWDD compared to the general population [22];

untreated caries was present in 32% of participants, while 80% had periodontitis. Frequencies of dental care visits are also lower in the AWDD population. A study in the city of Atlanta, showed that only 45% of AWDD visited a dentist at least once per year, compared with 58% in the control population [30].

Like many other population groups, factors that help to improve oral health status of AWDD include the ability to brush their teeth by themselves, having a regular dentist and living with friends or family rather than living independently or in an institution [31-33]. On the other hand, caregivers' knowledge, attitude, and behaviors towards AWDD play an important role. Many caregivers do not have the training required to provide good oral care for their developmentally disabled client or adult-child or to provide proper supervision of oral self-care.

1.5 Challenges in the provision of dental care

Providing dental treatment for AWDD is challenging for all members of the dental team, as well as for the family members, caregivers, and the AWDD themselves. In fact, it may be difficult for some AWDD to fully understand the need for dental treatment and, therefore, the need for their cooperation [34]. AWDD unable to cooperate during treatment are more likely to have extractions rather than restorations [28]. Further, diagnosis of acute dental problems like dental pain can also be difficult in these individuals who may have limited ability to express themselves. The dentists and dental team may also lack proper training in treating AWDD as well as lack rapport with the patient [35, 36]. As a result, dentists may choose to observe rather than treat a problem in these individuals. Similar to any Canadian adult, regular preventive maintenance including attending to dental problems at an early stage is the key to good oral health for AWDD's. A failure to receive timely dental care only increases the need for more complex treatment which in turn leads to increased costs [37].

Communication of oral health problems and pain can be a challenge for AWDD. In

Australia, a survey was performed to assess the oral health related quality of life (OHRQoL) of AWDD, from the perspective of their caregivers [38]. The authors noted that the prevalence of oral health problems were higher than the prevalence of reported negative impacts on quality of life. The authors also noted that a significant portion of caregivers were unable to assess the OHRQoL of the AWDD in their care with lower communication abilities [38].

Financial issues are also a significant challenge for AWDD's seeking oral care services. In British Columbia, the Ministry of Social Development (MSD) provides benefits up to $1000 worth of dental services every 2 years[8]. This amount may not be enough to cover the complex dental needs of some AWDD. Moreover the coverage that the government insurance provides is limited to 60% of the fee suggested by the British Columbia Dental Association[9]. This lower fee may not be acceptable to many dentists. Additionally, AWDD often require more time in the dental chair to receive treatment, a fact that increases the overhead costs [39].

Another consideration is the reduction of publicly funded dental clinics in Canada. Over the past 30 years while the total Canadian expenditure on dental care has increased from $1.3 billion in 1980 to $12.6 billion in 2011, the publically funded portion of this expenditure has decreased from 20% to 6%[10]. Therefore, lack of adequate dental coverage, reduced government funding and increased cost to treat AWDD individuals further hinder their access to oral healthcare.

1.6 Educating dentists to treat adults with developmental disabilities

The amount of training received by Canadian undergraduate dental students to provide care for AWDD varies across the dental faculties. The Commission of Dental Accreditation in Canada does require that "*Experiences in the management of medically-*

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[8] http://www.bccpd.bc.ca/docs/hs7.pdf Accessed November 26, 2013
[9] http://www.eia.gov.bc.ca/publicat/pdf/dentistschedule.pdf Accessed November 26, 2013
[10] http://www.fptdwg.ca/assets/PDF/Environmental_Scan.pdf Accessed November 26, 2013

compromised patients and patients with disabilities and/or chronic conditions, should be provided"[11] by accredited dental faculties, however there are no specific requirements about amount of procedures to be performed or minimum number of patients to treat. It should be noted that this is not specific to the AWDD population, as the Commission does not provide requirements for number of procedures to be completed on any segment of the population (i.e. geriatric, young children etc.). Also of note, the Commission uses the terminology "should" and not the word "must", leaving room for different dental faculties to fulfill the requirements within in the manner appropriate to their specific context.

In 2013, an undergraduate curriculum guidance document was developed by the international Association for Disability and oral Health (iADH)[12]. This document was designed to allow curriculum developers to provide dental students with greater opportunities in acquiring the skills and knowledge required to treat special needs patients. The guidance document is divided into 6 competency domains [40]:

1. Scope of special care dentistry
2. Access and barriers to oral health for people with disability and other marginalized groups
3. Consent for people requiring special care
4. Communications skills in special care dentistry
5. Impacts of impairments, disabilities and systemic conditions on oral health and oral function
6. Clinical management of patients requiring special care dentistry

The iADH has proposed that dental faculties across Canada include this guidance document within their individual curriculum, with the ultimate goal that better education of dental professionals will lead to better access to dental care for the special needs population [40].

Lack of proper training may be one of the factors contributing to the high levels of unease many dentists feel in treating AWDD. In fact, a University of Michigan study reported

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[11] http://www.cda-adc.ca/_files/cda/cdac/accreditation/qualifying_programs_2006_en.pdf Accessed March 20, 2014
[12] http://iadheducationdotorg.files.wordpress.com/2013/03/iadh-curriculum-document-at-undergraduate-level-for-download.pdf Accessed March 30, 2014

that only 35% of alumni and 41% of dental students "strongly agreed" that their dental education had adequately equipped them to treat the AWDD population. Only 47% of dental students strongly agreed with the statement *"I plan to treat adults with disabilities in my future practice"* [41]. Another study at the University of Michigan revealed that adult patients with autism were accepted by only 33% of general practitioners. Furthermore those respondents that felt they were better trained, were also more likely to actually treat adult autistic patients in their practice [42].

1.7 Current knowledge about access to care for AWDD

Studies of access to dental care for AWDD are sparse. A survey to determine the availability of dental care for group home AWDD patients in north central Florida [43], revealed that 40% of caretakers experienced difficulty in locating oral health care providers willing to provide comprehensive dental services. Providers were hesitant to provide services for a variety of reasons: financial disincentives, inexperience and lack of proper equipment [43]. Another U.S study examined the potential barriers to dental care for a selected sample of 57 adults with cerebral palsy; only 60 % of the participants were regular dental patients. The most common barriers cited were fear and negative attitudes from the AWDD participants, while cost was a rarely identified barrier [44].

An Australian survey enrolling 113 patients from 6 community dental clinics and 1 dental hospital demonstrated that 38% of participants had a general dental practitioner, 35% used the community dental service for care, and 27% accessed hospital dental services. Only 5 patients reported difficulties with travel and access to dental clinics [45]. Access to dental care was not a significant issue, as all AWDD individuals and AWDD caregivers/family members were already patients of the community dental clinics and dental hospitals. It is unlikely if the same results would occur in a population without such community-based care [45]. Moreover, investigators were not able to collect any information on the number of caregivers/family members that responded by proxy for the AWDD individuals in their care.

This disparity in access is not exclusive to the AWDD population, but also to ethnic minorities [46] and those of a lower socioeconomic status [47]. A survey of AWDD of minority background in the United States suggested that they are able to obtain medical care easier than dental care. In fact, the authors highlighted dental care specifically as an unmet health need for this population [48].

Most previous Canadian studies have involved children with developmental disabilities. Researchers from the early 1970's reported that 26% of Canadian children with cerebral palsy and 16% of children with Down syndrome experienced struggles obtaining dental care [49]. However a later study reported that parents seemed to be generally satisfied with the dental treatment that their child had received [50].Later in 2004, investigations reported that children with Down syndrome received dental treatment that differed quite significantly from their healthy siblings; they were less likely to have received a fluoride treatment or restorations but were more likely to have had extractions [51]

A contemporary study focusing on AWDD in the metro Toronto area has demonstrated that almost three-quarters of caregivers for AWDD patients reported no major issues in accessing dental services [39]. Further, the majority of persons with disabilities and most of their caregivers believed that oral health was important for overall health. [39]. The results also highlight the fact that internal patient factors such as inability to cooperate in a dental setting and dental anxiety are better correlated with greater barrier to dental access compared to external patient factors such as cost and transportation (Figure 3).

The findings of these studies should be interpreted with caution. Most respondents from larger cities are more likely to have better access to a dental office compared to those in a more rural area, while those AWDDs participating in a survey are also more likely to be less severely disabled. Like all other survey research, the results might also be skewed because of self-reporting bias, i.e. respondents want to respond in a way to portray themselves in the most positive light [52]. Therefore they tend to under-report behaviors that they think might be deemed unsuitable by the researcher [53]. It should also be noted

that the caregivers completed many of these surveys. Therefore some of the experiences from the perspective of AWDD may have been missed.

Table 2: Top 3 factors (internal/external) associated with barriers to access

Internal patient factors	External Patient Factors
Cooperation with dental treatment (19%)	Cost (16%)
Dental fear (18%)	Transportation difficulties (11%)
Perception of dental problems (6%)	Adequacy of dentist training (8%)

Source: Koneru, A. and M. J. Sigal (2009). "Access to dental care for persons with developmental disabilities in Ontario." Journal (Canadian Dental Association) **75**(2): 121.

In 2008, the UBC School of Social Work surveyed caregivers of AWDDs receiving services from Community Living British Columbia (the provincial crown agency mandated to deliver supports and services to AWDD individuals in British Columbia). One of the purposes of the study (named the Community Living Research Project or CLRP) was to gauge satisfaction with current supports and services. The results from the one item on the survey related to dental issues indicated that 79% of caregivers felt that AWDD had access to "appropriate dental services"[13]. Unfortunately, no further analysis was done with regards to the differences in services around the province or what was meant by "appropriate" services. An expressed concern related to this project was that caregivers completed the surveys rather than the individuals with the disability who might paint a different picture of access to dental services.

1.8 Lack of fit between the published literature and caregiver anecdotes

Based on some of the recent literature, the majority of those with disabilities claim to have no major issues with access to dental care [39, 45]. However anecdotal comments from caregivers and self-advocates (AWDD who can advocate for themselves) in British

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[13] http://cic.arts.ubc.ca/uploads/media/Community_Living_Services_Family_Member_Survey_Quantitative_Report_02-08-2010.pdf
Accessed November 26, 2013

Columbia tell a different story. Lack of transitional services for dental care i.e. services to help youth move on to adult focused care centers, few dental professionals willing and able to treat AWDD's and inadequate access to safe sedation and general anesthetic services are issues reported by frustrated family members, caregivers and self-advocates.

There are various explanations for the "lack of fit" between the published literature and the feedback from the AWDD community. Most of the published research is based on quantitative, mailed or Internet based surveys sent to clients affiliated with different AWDD service organizations. Such an approach has inherent limitations, one of which is sampling bias. Those AWDDs who are connected to such organizations and respond to a mail-out survey are likely more able to complete a survey independently and thus likely able to access dental care [54].

One issue with mailed or Internet-based surveys is the closed-ended questions that are most commonly used. The alternatives presented to respondents are limited in number and influenced by the researcher. However, open-ended questions may also be open to bias i.e. leading questions, but likely to a lesser degree. Indeed such questions may result in more spontaneous responses. [55] Another issue of concern is that of recall bias. In a survey where the questions asked are "period specific", the respondents may not be able to recollect the events correctly and therefore might answer questions inaccurately [39].

A difficult issue in any research involving the AWDD population is obtaining a representative sample. As mentioned previously, the definition of developmental disability is not uniform and there are multiple diagnoses that could be included [3]. This results in multiple levels of executive function ability and therefore affects issues like independence and cooperation ability. One solution for this issue is to stratify the population. For AWDD populations this stratification may include the spectrum from high executive functioning/verbal to lower executive function/non-verbal. For certain segments of the AWDD community, proxy representatives, i.e. parents or caregivers may be recruited to gain better insight into the individuals of interest.

Therefore, to further explore the issue of access to dental services for AWDD, an

exploratory, qualitative approach should be considered to gain a more in-depth understanding. Such an approach may help to bridge the gap between the published data and anecdotal reports. Qualitative research collects and analyzes the themes gathered from in-depth conversations with subjects regarding a specific area of interest. Qualitative approaches often produce insights unlikely to be gathered by traditional quantitative approaches. However, qualitative methods share some of the same limitations as quantitative research.

1.9 A brief summary of qualitative methods

A qualitative approach involves observations and open-ended questions that allow for deeper probing into the issues of concern. The initial design of qualitative research is similar to a "rough sketch" that needs to be refined by the researchers as the project progresses [56]. There are many types of qualitative research; two common methods, provided as examples only, are grounded theory and phenomenology.

Grounded theory is also known as "reverse engineered hypothesis" (Glaser and Strauss 1967). In grounded theory, rather than having a preconceived hypothesis to prove or disprove, the researcher focuses on different aspects of a phenomenon to generate a hypothesis [57]. The researchers look at the "data" gathered by, for example in-depth interviews or focus groups and from the different stakeholders perspectives. Next they carefully examine the information for concepts and their interrelationships. As the data collection and analysis progress, concepts are further refined to construct theories for the phenomenon observed [58].

In phenomenology, the investigators explore the experience of a phenomenon (also termed "lived experience") by an individual or a group [59]. A shared phenomenon may be a common condition, such as women who have been abused or children who are adopted [60]. The researchers attempt to gain access to the essence of the stakeholder's experience. The most common way of achieving this is by in-depth personal interviews. The interviews are analyzed for common experiences to attempt to locate and explain the universal nature of the experience [59].

Qualitative research presents the researcher with many unique challenges. One of the first issues to consider is that of sampling. Random sampling is not applicable to qualitative research; rather a "purposive" sampling strategy is often employed [61]. In this strategy, the researchers select only those individuals or groups who the researchers feel have the most to say about their research question. Sampling includes only these types of cases or individuals in focus groups or interviews [61].

Uniformity in sampling is another challenge. Any given phenomenon may have multiple "stakeholders". Each stakeholder has a unique relationship to the phenomenon in question [61]. For example a study of access to care may include not only the subjects who are attempting to gain access, but also family members and caregivers who enable or impede access. The lack of uniformity of respondents allows for understanding of multiple different perspectives of an area of interest [62]. However this lack of uniformity also presents multiple challenges, particularly related to data analysis. These "multiple different perspectives" introduce different confounding factors, for example social economic status, education and level of executive function that likely influence the responses given [62].

One useful tool in gaining insight to the stakeholder experience is the use of focus groups. Focus group discussions are guided, monitored and recorded by a facilitator, in order to uncover information on communal views and elucidate the meanings that provide the foundation for those views [63]. Focus groups also provide a deeper appreciation of participants' experiences and principles [64]. Open-ended questions give the subjects autonomy to present their own opinions and share their insights. Furthermore, these questions are designed to encourage the subjects to expand on their ideas without leading them to a specific or predetermined conclusion [65]. The job of the facilitator is to engage in active listening - a task that involves concentrating not only on "what is said", but also on "what is not said". Tone of voice, hesitation, and other verbal and physical cues may be important in understanding the intent of the subject as well as their true feelings regarding the issues [66]. An interview or topic guide is usually used to

direct a focus group. This guide allows for an organized coverage of pertinent issues without losing the flexibility of spontaneous discussion and it "lessens" the degree to which the researcher can influence the subjects' responses [67].

Focus groups also allow for interaction among participants, which is an important advantage over one-on-one interviews. This interaction can encourage participation from individuals who might otherwise be reluctant to be interviewed on their own [68]. Additionally, participants who might not initiate conversation may be stimulated to respond to the discourse of another member of the focus group [68].

Focus groups also present some disadvantages. One such disadvantage is the possibility that opinionated and willful participants may dominate the discussion thereby not allowing everyone in the group to share their perspective [63]. Further, even with efforts made to provide a welcoming and pleasant environment for the focus group, the fact remains that the environment is artificial and somewhat controlled. As a consequence the natural reaction and conduct of the participants may be altered [63].Furthermore, the researchers conducting the focus group may unintentionally lead participants towards certain preferred responses based on their own biases and experiences [63].

The ideal way for a researcher to recruit subjects is to develop and maintain a strong working relationship with individuals or organizations of interest [56]. Focus groups may be "naturally occurring" (people who have personal or working relationships, i.e. support groups), or may be convened specifically for research [68]. The advantage of naturally occurring groups is that the researcher may observe group interactions that add to the texture of the information gathered [68]. These participants should also feel more at ease to express their point of view and to disagree with other group members; such disagreements may encourage supplementary exploration of divergent opinions [69].

Qualitative data analysis typically begins after the initial data is gathered and transcribed. The analysis is continuous and is modified throughout the research project [70]. The initial data analysis informs further data collection. For example, interview questions may be modified to encourage responses or to make the questions easier to understand [69].

A method of data analysis commonly used in qualitative research is thematic analysis, which involves identifying codes, themes and domains that emerge from the data [71]. Following transcription and repetitive reading of the transcripts the "data" is coded. A code is a word or short phrase that summarizes a data segment [70, 72]. Once the data is coded, the codes are analyzed for overlap and similarities and then similar or related codes are grouped together into themes. A code differs from a theme in that a code attempts to summarize a portion of the data, while a theme attempts to identify what that data means to the researcher. Themes can then be grouped together under an overarching domain [73, 74]. The coding, analyzing and grouping process continues until data saturation is reached. Data saturation in qualitative research is defined as the point where the investigators no longer can identify new themes/domains or information from the data [70].

Once the themes are identified, the researcher produces a hierarchy of themes and looks for relationships between them [75]. These themes can be used to draw conclusions; however these conclusions are not always generalizable. This process also aids in developing more focused hypotheses to be tested with quantitative methods [3, 76].

2. Purpose

2.1 Research Problem

Access to quality oral health care is important for the AWDD community [77, 78]; however, previous research into the experiences of AWDD accessing dental care has been limited to quantitative surveys [39, 79, 80]. Results of these surveys suggest that access to dental care is not of great concern for AWDDs, but anecdotal reports from the AWDD community, their parents and from service organizations suggest otherwise. This research was undertaken to explore the issues of access to dental care for AWDDs in a more in-depth, qualitative manner than had previously been achieved with quantitative surveys.

2.2 Research Objectives

The objectives of this study involving adults with developmental disabilities (AWDD) in BC's Lower Mainland were to:

- Explore their experiences of accessing dental care.
- Determine the factors that enable or hinder their access to care and that affect their quality of experience.

2.3 Research Question

What are the experiences and challenges of AWDDs accessing dental care in the Lower Mainland of British Columbia?

3 Methods

3.1 Overall study design

To gain a deeper appreciation for the experiences of AWDD accessing dental care, a qualitative approach using focus groups was undertaken. Qualitative methodology was chosen to enhance the understanding of issues in access to dental care from the perspective of AWDD patients and their family members/caregivers.

Self-advocates and family members were invited to participate in focus groups to discuss their experiences of seeking and receiving dental treatment. The student researcher (AS) conducted these focus groups. In the case of focus groups consisting of AWDD self-advocates, advisors to the AWDD self-advocacy groups assisted with the process of recruitment and consent. However, for the most part, self-advocates participated independently in the focus groups.

Ethics approval was received from the University of British Columbia Behavioral Research Ethics Board (BREB). The initial research plan was to conduct focus groups only with self-advocates. However, as the study progressed and the data was analyzed, it became clear that engaging only with self-advocates had drawbacks. The major problem was our inability to include the experiences and "voices" of AWDD individuals with more severe executive functioning deficiencies (i.e. individuals not able to advocate for themselves). As a result, these AWDDs most likely to have the greatest barriers to dental care were being excluded. The challenge of how to involve individuals with serious communication and/or mobility difficulties remained.

The evolution of our study design was prompted after a discussion between the student researcher and a parent of one of the participating AWDD. This parent inquired as to why family members of AWDD individuals had not been asked to participate. When she heard the response that uniformity in the study sample was our concern, she simply stated *"but we (family members/care-givers) are the voices of AWDD who cannot speak for themselves."* It soon became clear that the best, and perhaps only, way of including the voices of the more severely affected AWDD individuals was to invite family members and caregivers to participate. As such, a second phase was added to the study to include family member and caregivers. An addendum for the ethics approval to extend the study to family members and care givers was approved by UBC BREB.

The student researcher facilitated the focus group sessions, which were audiotaped. He transcribed the first two focus groups; the final three focus group recordings were transcribed by a professional transcription service. The time for each focus group was on average 40 minutes.

3.2 Sampling

3.2.1 Recruitment (self-advocates)

During the recruitment phase, three community-based service organizations were contacted to participate. These organizations were contacted because they represented the largest organizations supporting AWDD in the Lower Mainland of British Columbia.

Another reason for selecting these organizations was the fact that each had a self-advocacy group that met regularly. Of the three contacted organizations, two agreed to participate. The reasons given to the researchers from the non-participating organization were "research fatigue" and a lack of available time in the yearly schedule.

The participating community AWDD service organizations were the Burnaby Association for Community Inclusion (BACI) and Communitas Supportive Care Society (CSCS), which operates in Abbotsford. These two organizations provide assistance to members of the AWDD community over a wide range of areas including skills training, social and recreational activities, and employment opportunities.

A purposive sampling technique was used. It was important to target AWDD who had had dental "experience", therefore increasing the likelihood of gaining some insight into their perceptions of challenges with access. As such, the initial phase of recruitment targeted AWDD self-advocates who were likely to be at the higher end of executive functional ability and likely to be more comfortable and able to relay their experiences.

It is imperative that a qualitative researcher develops a relationship with the participants in an effort to foster a safe environment where meaningful communication can take place. Therefore, the student researcher visited the self-advocate monthly meetings as an invited guest, prior to commencing data collection. At these visits, the student researcher participated in conversations on topics pertinent to the AWDD community (issues that were not necessarily related to dentistry). At the end of the meetings, the student researcher was asked to present a brief summary of the research project and invite any interested members of the self-advocacy group to participate. The group members were then given a written consent form that outlined what would be required of the participants and how their privacy would be protected. Advisors to the self-advocate groups were present to help members with any difficulties understanding the consent forms (Appendix 1). All focus groups were held at meeting rooms in the offices of the participating service organizations.

3.2.2 Inclusion Criteria (Self-Advocates)

- Adults with developmental disabilities (17 years and older)
- Verbal
- Attends AWDD self-advocacy meetings

3.2.3 Recruitment (Family Members)

The participants in the final three focus groups were family members belonging to support groups. These support groups included the Family Support Institute (FMI) and the Family Support Group for Families of Mentally Handicapped Adults Society (FSG). These organizations were recruited to participate based on the recommendation of participants of the first phase of the study. Members met regularly to discuss important issues to the AWDD community. Support groups are an important source for networking among family members of AWDD individuals; as such they are an important resource when it comes to selection of a provider for medical and dental health care. All participants in this phase of the research had an AWDD family member who was dependent on them for care, either full-time or part-time.

Members of these support groups were invited to an informal meeting where the student researcher delivered a brief presentation on the objectives and design of the research project. Each member of the support group in attendance was then given time to introduce themselves and the AWDD family member in their care. These introductions enabled the researcher to get to know the circumstances of potential participants. The attendees were then invited to participate and provide consent (Appendix 2). Focus groups were then scheduled for those interested and were held in locations where the support group usually held meetings.

3.2.4 Inclusion Criteria (Family members)

- Family member or caregiver providing full-time or part-time care
- Attends AWDD family member/caregiver support group meetings

3.3 Data collection instrument:

An interview guide for AWDD self-advocates was designed and guided by the previous surveys and on questions about access that arose from discussions of the supervisory committee [39, 45]. The items were modified to be open-ended, thus allowing for increased interaction and debate amongst subjects (Appendix 3). Questions attempted to address the dental experience of the subjects, their attitudes towards oral health and their history of access to dental care. The supervisory committee reviewed and discussed all questions until a consensus was achieved on the nine-item interview guide.

The interview guide was reviewed and modified in an iterative fashion after each focus group. Subsequent to each focus group the data was reviewed to assess whether any question in the guide was redundant or failed to elicit response and discussion. The interview guide was finally modified to include six items (Appendix 4). A second interview guide was designed for the focus groups for family members (Appendix 5). Each participant was also given a twelve-item pre-focus group questionnaire for obtaining demographic data (Appendix 6). The participating family members answered this questionnaire on behalf of their dependent adult child with developmental disabilities. Participants were informed that they could leave answers blank for any questions they did not understand or preferred not to answer.

3.4 Achieving saturation

A process of data analysis concurrent with data collection was undertaken. The research supervisors and the student researcher reviewed the transcripts of each focus group to determine if data saturation had been achieved. After two self-advocate focus groups and three caregiver/family member focus groups, it was felt that the goal of data saturation had been fulfilled.

3.5 Data analysis

Pseudonyms were used in the transcripts to maintain confidentiality of participants. Thematic analysis was the approach used to analyze the information. Initially, the transcripts were reviewed for general themes as described in the "5 A's of Access" [19];

affordability, availability, accessibility, accommodation and acceptability. However, after reviewing the early stages of the analysis, it was decided that using pre-defined themes was focused and narrow. The scope of the analysis was then modified by moving into an "open coding" approach, which allowed for gaining richer information from the transcripts.

Open coding is a process where transcripts are coded line by line without the use of any preconceived ideas [81]. This process is concerned with *"identifying, categorizing and describing phenomena found in the text"* driven by the following questions: "*what is this about? What is being referenced here?*" [82]. Based on principles of open coding, an iterative thematic analysis approach was used where a particular code was assigned to each relevant set of words or phrase from the transcripts. This process helped to identify repeating ideas, which were then categorized as emerging themes. The themes were then categorized together under various domains (Figure 4).

It was primarily the research question and interview guide that guided the information obtained. However, as with any interview or group discussion, some of what was said by the participants was not directly relevant to the specific research questions but was discussion related to specific questions the participants asked the student researcher. For example, discussions regarding the most recent dental treatments and procedures available, such as dental implant therapy and dental bleaching occurred at the request of the participants. These discussions arose based on interactions among participants, where anecdotes regarding treatment experiences were shared. These "side-discussions" helped inform some of the codes and themes developed from the data and were also included in the coding process.

Figure 2: The Communication Domain with themes and codes
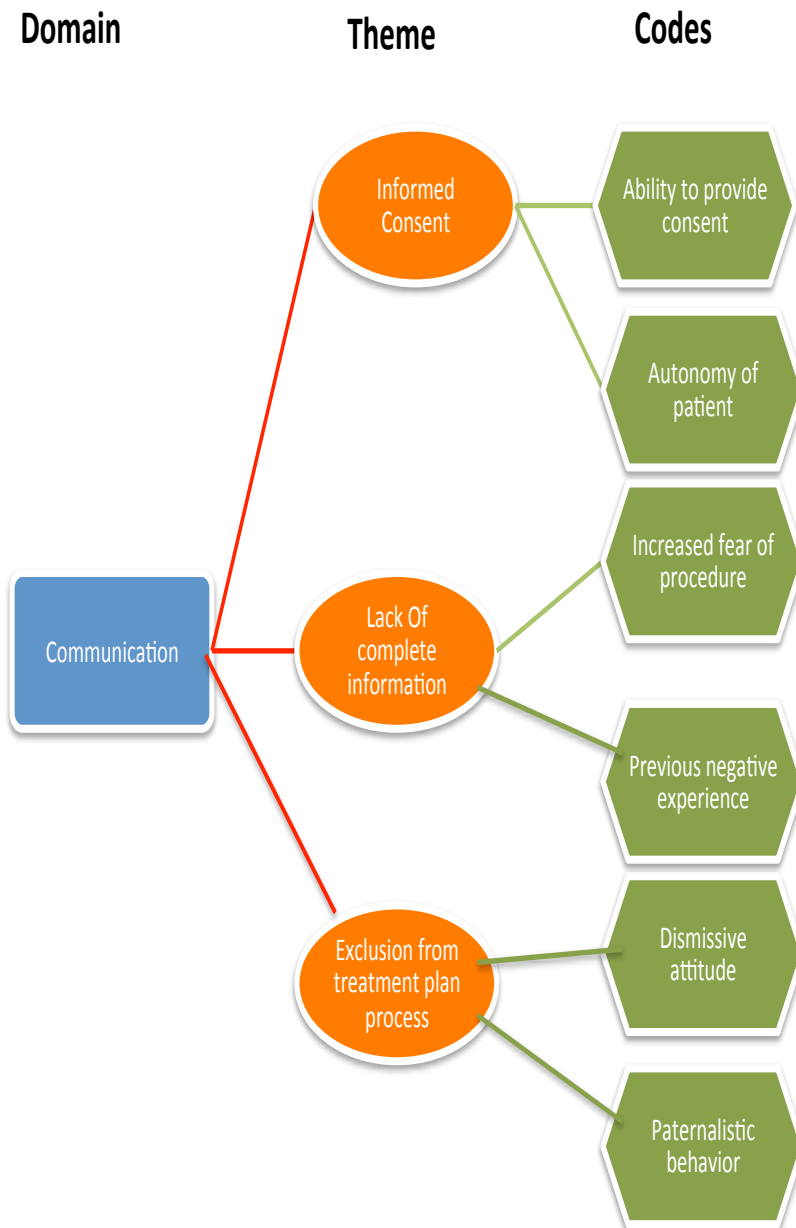
4. Results

4.1 Road map

The results are presented as follows. First, the information about participant demographics and characteristics acquired from the pre-focus group questionnaire is presented. Following that, the domains understood and interpreted from the data and some of the associated themes (underlined) are presented. Accompanying quotes from the different focus groups are provided (in italics) to support the themes and domains that emerged.

4.2 Participant characteristics

Five focus groups with 20 participants in total were conducted over a 9-month period in 2013. Two focus groups included AWDD self-advocates; three involved family members. One of the participants in the self-advocate group was a caregiver who assisted and "spoke on behalf of" a participant who was not able to speak for herself. The "comments" from this participant were included with the self-advocate group. Nine out of ten participants in the family member group were mothers of AWDD individuals; one participant was a father. Therefore, hereafter the family member groups are called the "parent groups". Items about age, type of disabilities, living situation, history of need for general anesthesia, travel time to a dental office and frequency of dental visits were included (Table 1 and 2).

The age range of the self-advocates was 26-60 years; the dependent AWDDs represented by their parent ranged from 17-42 years of age. Some of the older self-advocates had previously been residents of institutions such as Woodlands, a now closed facility

previously providing full-time care for AWDD in British Columbia[14]; Younger participants did not have that experience of institutional care.

Responses in the self-advocate group regarding diagnosis ranged from medically defined conditions e.g. Asperger's Syndrome to self- descriptions such as "don't read or write." To respect the privacy and comfort level of participants, no attempts were made to determine specific medical diagnoses from their physicians. Using a more personal description allowed for an appreciation of how each participant viewed their disability. In the parent group, responses regarding diagnosis were more "medically-correct"; autism spectrum disorder was the most commonly reported diagnosis.

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[14] http://www.inclusionbc.org/our-priority-areas/disability-supports/institutions/woodlands-insitution Accessed July 21, 2014

Table 3: Characteristics of self-advocates

Participant	Age	Developmental Disability	Living Situation	Frequency of Dental visits	Required General Anesthesia	Distance to Dental Office (Min)
# 1	60	"One side of my body does not work as well"	Group home	"When the nurse lets me know"	Yes	30
# 2	32	"I have a visual impairment"	Not Reported	Not Reported	Yes	Not Reported
# 3	60	"Brain Damage"	Fully Independent	"About four times a year"	No	30
# 4	Not Reported	"I have Asperger's syndrome"	Fully Independent	"When dental work is needed"	Yes	Not Reported
# 5	26	Not Reported	With Family	"Every 6 months"	No	30
# 6	NR	"Cerebral Palsy"	Not Reported	"2X per year"	Yes	30
# 7	60	"Don't read or write"	Fully Independent	"2 times per year"	Yes	10
# 8	36	"High functioning autism"	Independent with support	"2 times per year"	No	45
# 9	54	"Developmental disability"	Independent with support	"Regularly"	No	10
# 10	29	"High functioning autism"	Fully Independent	"Every 6 months"	Yes	20

Table 4: Characteristics of AWDD dependents of parent group

Participants	Age	Developmental Disability	Living Situation	Frequency of Dental visit	Required General Anesthetic	Distance to Dental office (Min)
# 1	31	Cerebral palsy	Group home	Once per year	Yes	45
# 2	17	Severe global delay	With Family	Every 4 months	Yes	30
#3	21	Autism	Independent with support	Every 3 months	Yes	30
# 4	24	Down syndrome/Autism	With Family	Does not have regular dentist	Yes	Not Reported
# 5	35	Down syndrome	With Family	Every 3 months	No	30
# 6	34	Mental disability	With Family	Yearly	Yes	25
# 7	42	Autism	With Family	Yearly	Yes	1 hour
# 8	21	Autism spectrum disorder	With Family	Twice per year	No	15
# 9	24	Chromosomal abnormality	With Family	6-8 months	Yes	20
#10	37	Autism	With Family	Once per year	Yes	2 hours

4.3 Thematic analysis

Seven domains relating to the experiences with dental care of self-advocates and of the parents' dependents emerged from the focus groups. These domains were

- Communication
- Trust
- Respect
- Financial constraints
- Transitional services
- Wait times
- Positive experiences

The domains may overlap in meaning and implication. For each domain, the corresponding themes are <u>underlined</u> in the text and the participants' quotes are presented *(in italics)* as exemplars of the themes. Confidentiality has been maintained by using the participant's assigned subject number from Tables 1 and 2.

4.3.1 Communication

Issues of communication emerged as a domain. No other dental experiences elicited a more emotional response from participants than those related to treatment being performed without appropriate communication or consent. Comments like *"they stole her teeth"* or *"the dentist should have to pay for her implants"* were responses suggesting that improper or inadequate communication had been an experience.

Many a self-advocate expressed frustration with a <u>lack of complete information</u> and a lack of opportunity for <u>informed consent</u> prior and during treatment. One self-advocate (FG1-#2) commented:

> *"I don't know what you're doing. You're poking around in my mouth. I
> don't know what you're doing, and you're not even telling me what you're
> doing?"*

Others discussed difficulty in self-expression. One self-advocate (FG1- #4) stated:

> *"So sometimes you get scared how they do a complaint sometimes because
> people can get scared even doing that, when you face a person who says,
> God, I don't know how to speak up for myself"*

However this experience of less than ideal communication was not universal. Indeed some self-advocates experienced satisfactory communication. One self-advocate (FG1-#1) stated:

> *"one of the reasons why I like him is because he explains as he's going along
> what he's actually doing instead of us just sitting in the chair and he's
> working on our mouth"*

Some parents felt they were excluded from treatment decisions. This denial of participation in the decision-making process was a decisive factor in prompting caregivers to change providers. One parent (FG2-#2) stated:

> *"She's had some bad experiences, though. Years ago she had a toothache
> in her upper teeth, and the dentist just decided to take all her teeth out
> without talking to anybody"*

Other parents (FG3-#2) related better experiences of communication, even commenting on the practitioner's collaborative approach:

> *"I'm hoping to have in our future dental relationship is one where it
> continues to be a collaborative relationship where the dentist is working
> with us as a group, as a team around our son. And I think that, for us, is*

what we're holding out for. It seems to be a much better approach because
we continue to be his voice and quite likely, for the rest of his life, we'll be
his voice."

It is of note that many of the experiences related to <u>clear communication</u> were not only between the dentist and the parent, but also between the dental office support staff and the parent. One parent (FG3-#2) stated:

"if he's having a bad day and they need to kind of get him in, I know that the
receptionist is gonna run defense for us even though there will probably be a
few people who say, "Wait a minute. I was here first." I know that she's gonna
look after that so I don't have to come out and defend my son's need"

Overall, while experiences of communication were a mixture of positive and negative experiences, analysis of responses confirmed the essential importance of clear, open and respectful communication amongst all parties.

Issues of communication between AWDD and their parents were also discussed. Some parents expressed frustration with their <u>difficulty in determining when and if their dependents had oral health issues</u>. One parent (FG3-#3) remarked:

"He doesn't have the ability to describe his pain at that level.
Behaviorally, he will act out when he has pain but that could be anything
from a headache to a toothache to anxiety to he doesn't like his brother!"

Other parents had comments related to this same theme in relation to their observations of the spectrum of pain tolerance in their child. One parent (FG4-#3) stated:

I mean, even when he had all the gum work done, they gave minimum
freezing, and he was in that chair for literally hours, and he just... I don't
know if he has a high pain threshold or what, but he just takes it.

Overall, parents and likely other caregivers are challenged in making decisions about when to seek oral health care for their dependent adult children because of problematic communication.

4.3.2 Trust

The domain of trust was common to both self-advocates and parents. Throughout the discussion, some self-advocates hinted at the issue of trust in their dentist. As a follow up to these comments, the self-advocates were simply asked if they "trusted their dentist." Most respondents answered positively. When asked why they trusted their dentist, a number spoke of their dental care provider being "gentle". The perceived "gentleness" of the provider helped to build trust. One self-advocate (FG1-#1) stated:

> *"Too bad you didn't go to my dentist, the gentle dentist."*

Several participants stated that their provider delivered "pain-free" dental services and statements such as "gentle injection" and "gentle cleaning" were made. Overall, a provider's gentle manner developed a feeling of trust.

Other self-advocates cited trust in knowledge and ability of the dentist as an important factor. Referring to the fact that her dentist was aware of all her medication and allergies, one self-advocate stated (FG1-#1)

> *"They actually keep track of your allergies and stuff, not just give you anything, so you don't have allergic reactions and stuff... He keeps on top of things and stuff like that..."*

Several parents discussed the importance to them as caregiver parents of having dentists that they could trust. One participant (FG3-#2) stated:

"*We didn't even know how to navigate the process so when Children's graciously [laughs] released us… we were at a loss because that was the dentist that we had the most trust and confidence in*"

Parents also related the importance of the dentist trusting them to help during treatment. One participant (FG3-#2) stated:

"*They would turn to us to ask, knowing that we knew him best. So they trusted us to provide information around, "Is he feeling pain? Do you think he's had enough?" That sort of stuff. And so that was really helpful*"

4.3.3 Respect

The issue of feeling respected and equal is important in the AWDD community and is no different in the dental setting. While participants were not directly asked if they felt respected or, on the other hand, felt stigmatized during their experiences of dental care, issues of feeling valued and respected were mentioned. Parents were also deeply concerned with the issue of 'respect' and stated that it was an important factor in choosing dental providers. Respect for personal choice was important for self-advocates to enhance their comfort in the dental office.

Several participants talked about the importance of feeling respected and treated equally in a dental office. One self-advocate (FG1-#1) stated:

"*They also don't just go ahead and treat you like a nobody. They believe that people that are disabled or not deserve to be treated with respect and that everyone has gifts and talents and a brain*"

Parents also talked about the importance of dentists being respectful. Respectful language and demeanor were cited as important factors with one parent (FG3-#2) stating:

"I think what worked well for us at Children's was the language that they used. They were careful and they were always respectful"

4.3.4 Financial Issues

Simply affording dental care is a universal concern. Several participants mentioned issues of the high cost of care and inadequate insurance coverage. However parents had the most to say related to the financial domain. However, several self-advocates did have concerns about the high cost of dental treatment. One (FG1#-4) stated:

"Well, the closest experience I had was about a root canal. And this is last year. Because I was being confused what they were explaining to but when I saw the cost, a lot of people who are low income can't afford it"

Other participant's related stories about having to forgo dental treatment due to lack of adequate dental insurance. One self-advocate stated (FG2-#3):

"... he was very displeased once when he couldn't put a silver filling in because they're $300 each, and the Medicare or what is it, the dental thing, they didn't cover it, so he couldn't put all the silver fillings in"

Another participant (FG2-#1) related:

"And as far as I'm concerned, it's not enough because just alone for my partial plate… because I ended up sneezing one day before I ended up getting the proper clips put on my teeth. I ended up sneezing this one day and my plate came out of my mouth and I didn't see where it landed and I stepped on it and it broke – not just in one spot. It broke in three different spots. [laughs] I went to the dentist's office and they go, "We're sorry, Mr. X, but it's not covered."

The issues of the cost of dental treatment were prominent for parents, as most of their AWDD dependents had no independent source of income. In turn, the responsibility of payment of dental expenses was that of the parents. Almost all parents stated that they would like to have more financial support to help with dental expenses. Some parents shared stories of difficulties they faced because of their inability to afford dental treatment. One parent (FG4-#1) stated:

> "*I'm in a real jam…They all know there's a money problem here… I'm seeing already there's food that he just can't or won't eat now. And he really enjoys his food. You know, I hate that pleasure being taken away from him…*"

4.3.5 Transitional Services

The challenge of transitional services arose as a domain. Transitional services are defined as "purposeful and planned process where the care of individuals with chronic healthcare needs is transferred from child-oriented facilities to facilities that cater to adults"[15]. Self-advocates talked about lack of a referral system between providers. Most self-advocates depended on either family members or a service organization in helping with transitioning their medical and dental care into adult facilities. Several participants discussed not knowing where to go when they lost the services of a previous dentist. One participant (FG2-#2) talked about not being provided with any guidance when her dentist retired:

> "*AWDD: It was hard to get used to her. It was sad having the old dentist leave. I had him for many years and it's kind of like… umm…*
>
> *Mod: Did your old dentist refer you; send you to this new female dentist?*
>
> *AWDD: No, he just moved on.*"

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[15] http://www.cps.ca/documents/position/transition-youth-special-needs Accessed July 24, 2014

In the parent group, the <u>transition from a pediatric to an adult facility</u> was a recurring issue. . Most parents stated that they had to use their <u>own networks of family/caregiver support groups</u> to locate a dentist for their dependents. One participant (FG3-#2) discussed her frustration with different experiences she had when it came to transitioning her son's medical and dental care:

> *"that flow wasn't the same flow for our doctor to then refer him to the dentist.*
> *He didn't have access or knowledge as to whom he would possibly refer us to.*
> *So I think that that was what we were missing is, so where do we go now?"*

Other parents discussed the difficulty that caregivers face when they "lose" (due to retirement or relocation) a trusted dentist. One mother (FG3-#4) described the <u>frustration of finding a new provider</u>:

> *"Our major challenge is really finding someone… We didn't even know how*
> *to navigate the process when Children's graciously [laughs] released us"*

4.3.6 Wait Times

Both groups expressed frustrations with <u>long wait times</u> for treatment. Self-advocates who required <u>additional services</u> like sedation or general anesthesia, were most likely to mention long wait times. One participant (FG1-#1) related an experience that he/she had while waiting for treatment under a general anesthesia:

> *"And then you go through all of that, the so-called 20-some-odd month waiting*
> *list or whatever, and then the next thing you know, you can't even get into the*
> *program that you were wanting to get into in the first place because the*
> *position or spot that you were wanting in that program, oh, well that's already*
> *filled!"*

All parents whose dependents required general anesthetic services stated that they found wait times for the service to be unacceptably long. With the additional problem of communication difficulties, many expressed fear that their dependent might be suffering without their knowledge. When one parent mentioned feeling "pretty good" that her daughter had to wait only eight months for dental services, another parent (FG3-#2) remarked:

> *"the fact that that was "pretty good" makes me scared. Because for me, if I had a toothache, eight months is not "pretty good." Eight months is atrocious, right?"*

4.3.7 Positive Experiences

The many positive experiences with dental providers that self-advocates and parents described emerged as an overall domain. Such experiences made the dental visit more pleasant and appreciated. These experiences are important to consider and convey.

A welcoming atmosphere and concern for discomfort during treatment were common reasons for a positive experience as reported by self-advocates. One participant (FG1-#3) stated:

> *"They actually try to make you feel at home. Like, they put sunglasses on people so they don't get uneasy. They have a television in the waiting room, which makes it more homelike"*

Another self-advocate (FG2-#2) remarked:

> *"...and I was scared when I heard. So they're being very wise with me with that. And I said, "Please, thanks for telling me".*

Several parents discussed the importance of special accommodations being made to allow for a more positive experience. Factors such as timing of appointments, less time spent in waiting rooms and having special services were mentioned. One parent (FG3-#2) stated:

> *"...need to have the ability to provide that kind of accommodation to say when a patient comes in with special needs that, We drop everything and we don't make them wait for 20 minutes,"*

Another parent (FG5-#2) remarked:

> *"Because they have that service (sedation) available, because not every dentist can do that, right."*

Overall participants in both groups had a variety of positive experiences and suggestions to share.

5. Discussion

This research explored the experiences of AWDD accessing dental care. Previous quantitative surveys on this topic offered limited insight into the experiences of AWDD and seem to be at odds with anecdotal reports of concerned parents, service organizations and AWDDs themselves [38, 39]. Our objectives were to gain a deeper understanding of barriers AWDD face accessing dental care and to explore their positive and negative experiences of care. Using a qualitative approach, seven domains emerged which frame the experiences of the AWDD community accessing dental care.

A short questionnaire completed by self-advocates and parents prior to the focus groups helped us understand the characteristics of our participants. Six out of ten participants in the self-advocate group had visited a dentist more than once per year. Nine out of ten participants in the parent group also said that they accompanied their dependent AWDD

to a dentist more than once per year. The latest Canadian survey reported that about 74% of the general population had seen a dental professional in the previous year[16]. This similarity in attendance rates may be attributed to the fact that our participants were involved with advocacy and support groups and cannot be understood to be representative of the entire population of AWDDs in BC's Lower Mainland. The self-advocate participants were relatively high functioning and therefore more likely to be adept at finding a dentist and traveling to appointments compared to more severely compromised individuals. Parent participants who were members of support groups were also likely to have a network through which they could find a dentist for their dependent adult child. In the high functioning self-advocate group, most respondents' living situations were either fully independent or independent with assistance. In the parent group, most of their dependents lived at home with them. Extensive travel time to a dental office was not commonly reported although one parent mentioned a 2-hour commute to a dentist.

Prior to discussing the domains that emerged, it should be noted that participants were asked to relate any experiences where they or their dependents needed emergency dental treatment but could not access these services. It is reassuring that no one offered an example of such an event. These results may suggest that finding a dentist, even for emergency care, was not necessarily a problem for the self-advocates or for the dependents. However, there is a difference between simply visiting a dentist and feeling that the ideal or best quality care is being offered [83]. We explored the periodicity of dental visits and access to emergency care when needed, but did not really explore whether self-advocates or parents felt confident that "ideal" care was available to them.

Most participants knew each other previously because they belonged to the same advocacy and support groups, which may have enhanced their comfort to speak candidly. All were encouraged to respond to each other's statements even if they had a contradictory point of view. Participants were encouraged to voice their opinions using respectful language and to give examples to support their arguments. This type of group

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[16] http://www.hc-sc.gc.ca/hl-vs/pubs/oral-bucco/fact-fiche-oral-bucco-stat-eng.php Accessed July 24, 2014

dynamic enabled minimal intervention from the facilitator and improved the flow of discussions [69].

Overall, seven domains related to experiences of dental care and access to care emerged. One domain was communication. "Breakdown" of communication has been found to be an important factor contributing to health care inequalities by other research involving the AWDD community [84, 85]. The researchers postulated that effective communication is important in areas related to providing individuals with complete information about medical conditions, treatment alternatives and the availability of services. In our self-advocate group, several participants expressed their satisfaction with the level of communication they enjoyed with their current dentist. However, a number of participants gave examples of poor communication that resulted in frustration and anger. The core issue in many of these examples was an underestimation by the provider of the communication abilities (verbal or non-verbal) of the self-advocates. Our self-advocate participants were all verbal and high functioning and therefore able to communicate relatively well.

Other studies that have examined communication with more severely affected AWDD have suggested the over reliance on verbal communication techniques (even with non-verbal subjects) and the predominant use of directives is a core reason for communication failure [86]. The difficulty that most health professionals have in gauging and modifying communication techniques to best match those of patients with intellectual disability is an important consideration. A study of communications involving 22 adults with intellectual disability reported that even a majority of caregivers were unable to adapt their communication skills to that of AWDD. Usually, communication was beyond the understanding skills of the AWDD [87]. The skill of determining the communicative ability of the AWDD and maintaining a balance of verbal and non-verbal communication is of utmost importance; however such a skill likely requires not only training but also patience. Not surprisingly, the iADH has recommended "communication skills in special care dentistry" as one of 6 domains for dental curriculum developers to provide further

dentists with greater opportunities to acquire the skills needed to provide care for AWDD [40].

When examples of communication problems arose in the focus groups, other participants often had strong reactions. For example, whenever participants mentioned their perception of having treatment without their consent, others were quick to interject with comments such as "they stole her teeth" and "the dentist should have his/her teeth pulled out". These responses imply the concept of informed consent. Several previous studies have examined the difficulty of ascertaining the ability of AWDD to provide informed consent. These studies concluded that AWDD with severe functional deficits are particularly vulnerable to exploitation and that having clear rules and regulations can help clarify the responsibilities of health care providers [88, 89].

Our study focused on the perspective of AWDD and caregiver parents. Some of our self-advocates felt that they were not given the proper opportunity to provide informed consent. While we made no effort to verify the "validity" of this perception, if our participants viewed lack of consent as a problem, their concern must be interpreted as a valid communication issue. Sadly, the threat of dental treatment as a form of punishment has been reported in the past in some North American psychiatric hospitals and residential long-term care institutions [90]. As noted previously, several of our participants had experience living in such institutions in British Columbia. Therefore, their perception of dentistry has likely been negatively affected by such experiences and they may have been more likely to have an emotional response to issues of consent to treatment.

Communication "breakdowns" were not solely between dental provider and AWDD patients. Both of our study groups gave examples of communication difficulty between parents and AWDD. The issue of an inability to determine pain and discomfort levels related to oral health problems was a major difficulty cited by family members. AWDD may be limited in their ability to self-report pain intensity and duration [91]. Therefore, caregivers may not always be able to determine when it is appropriate to seek emergency

dental care; this delay may lead to long-term discomfort, which may adversely affect behavior. In fact, Carr et al reported that behavior problems observed in AWDD patient's initial assessments were correlated to their amount and intensity of pain. [92].

Of course, communication challenges are not unique to the AWDD population. Other studies of access to dental care in "disenfranchised" populations such as indigenous groups and the poor have cited lack of proper communication as a crucial barrier to access [93, 94]. However, the challenges of having a developmental disability adds a further confounding factor [95]. The quality of communication has a direct effect on the quality of experience; thus, poor communication could be construed as a key barrier to accessing the best of care [83]. Therefore when our participants gave examples of less than ideal communication, they may have indirectly been questioning the quality of the dental services that they received.

Another domain that emerged from our interpretation of the transcripts was that of trust. Certainly trust is imperative in any provider-patient relationship [96, 97]. The majority of participants in both groups stated that they trusted their (and their AWDD dependent's) current dentist. Self-advocates seemed to generally equate trust to a perception of "gentleness" or "empathy" from their dentist. Efforts by dentists to show empathy to AWDD will certainly build better bonds of trust between AWDD and provider. Certainly, provider empathy is appreciated by all vulnerable individuals [98].

Two of our self-advocates suggested that negative experiences related to inadequate anesthesia during treatment were a reason for losing trust in their dentist. Previous reports suggest that dentists sometimes avoid local anesthesia injections for fear that the injection itself may cause elevated anxiety. Of course, the result is poor pain control during treatment [99]. This rather startling phenomenon of inadequate anesthesia has been reported in other vulnerable groups, including patients living with HIV [100] or major depressive disorder [101].

Parents described how being allowed to help in the dental setting enhanced their trust of their dependent "child's" dentist. They were enthused to be advocates for their child. Several parents acknowledged that while their dependents were adults their role as an advocate was still critical. Therefore, an acknowledgment by dentists of the advocacy role that parents play will aid in fostering a trusting relationship between parents and dentists which in turn can only improve the perceptions of quality of care [102]. Several parents acknowledged the fact that their adult child's dependency would indeed be a lifelong engagement. This special relationship is an important issue that needs to be taken into consideration when decisions are made in regards to including family members or other caregivers in aiding with treatment

The domain of respect also emerged from both groups as an important factor in choosing a healthcare provider. When self-advocates were questioned in regards to specific reasons related to why they felt respected, the responses varied from "demeanor in interactions in part of the provider" to "staff friendliness and accommodation". Given the history of inequity faced by the developmentally disabled, the concept of respect takes on even more significance [103]. In fact, inequality or a lack of respect is a factor affecting the perceived quality of the dental experience [104, 105]. While not one self-advocate participant provided an example of disrespect in a dental treatment setting, they did use phrases like "being treated as an equal" and "being valued" as important to their satisfaction with care.

The cost and affordability of dental care was another domain. Participants provided examples of treatment delayed or avoided because of financial constraints. Depending on the type and extent of dental treatment required, the current publicly funded dental benefits for persons with disabilities are often insufficient to cover costs [106-108]. Compounding the problem is the fact that the AWDD, for a variety of reasons, have increased risk to oral health problems [22]. Of course, the issue of the financial burden of dental care in British Columbia is not exclusive to the AWDD population [109] and this domain is a barrier to access to care for most vulnerable groups.

While the financial burden of dental care emerged from the focus groups, the issue was not the primary barrier to care that others have reported [110, 111]. One reason for this difference may have been because our self-advocates were quite high functioning and thus may have been more adept at maintaining reasonable self-care at home and regularly visiting a dentist. Their preventive maintenance may have meant they did not tend to require expensive dental rehabilitation. Both our self-advocates and the parents reported regular attendance at dental offices, which hopefully included preventive dental services. AWDD who can maintain optimum homecare oral health practices have been reported to suffer less from oral disease [112].

Another domain discussed was transitional services. Many individuals with developmental disability are able to make the transition adequately, but others face serious gaps in care. Additionally, the more severely an AWDD individual is compromised, the more difficult the transition becomes [113, 114]. Several parents expressed their frustration with transitioning from pediatric dental to adult dental facilities. Of note is that the same difficult transition was not mentioned for medical services. Several participants spoke of no clear direction on where to go or no information on who would be in charge of the dental needs of their dependents after discharge from facilities for children. This lack of guidance can be a barrier to dental care and increase the difficulty families and caregivers have in organizing and arranging their dependents already difficult schedules of medical and dental appointments.

The difference between the ease of transitional services for medical and dental care may be attributed to the fact that the primary care physician (pediatrician or family doctor) acts as a "quarterback" to coordinate medical services and transitional care [115]. However, the same arrangement has not been formally implemented in dentistry. One could hypothesize that the problem may be compounded by the fact that once AWDD parent and caregiver networks become aware of a dental office willing and able to treat AWDDs, a sudden influx of patients may overwhelm the practitioner. Several participants had stories of willing dentists who no longer accept new patients after an influx of new AWDD patients.

Another domain that emerged was that of wait times. Frustration was expressed with the length of wait times experienced, especially if general anesthesia or sedation was needed to enable treatment. Other authors have addressed the issue of wait times. A recent survey of Canadian doctors reported that they believe that on average their patient's wait three weeks longer than what they consider clinically "reasonable" for elective treatment [116]. Further, individuals who perceived wait times to be shorter also reported a higher satisfaction score with the medical procedure [117]. While we did not probe further for a relationship between wait times and perceived quality and satisfaction with dental care, such further inquiry is warranted.

Wait times for dental treatment under general anesthesia was a particular source of frustration and is an ongoing problem in most jurisdictions. The Canadian Pediatric Society recent position statement suggests that only about half of child patients are treated within a medically acceptable wait-time [118]. Others have reported waiting times of up to 40-60 weeks in pediatric institutions [119]. While no published data is available, anecdotal reports from parents and caregivers suggest that these wait times are even greater in adult facilities and hospitals. Long wait times further compound parent's fear of their dependents existing with prolonged pain and suffering. This concern adds to the existing daily stress that many caregivers experience. Negative health impacts related to the stress and worry of caring for disabled dependents have been reported for caregivers [120].

The many positive experiences of the participants with the dental profession emerged as a separate domain. Participants from both groups were forthcoming with examples of positive experiences. The themes that were most commonly related to a positive experience by the self-advocates were a welcoming atmosphere and empathy for any discomfort. These themes were represented by reports of the friendliness of the dental team, the use of entertainment systems in the dental operatory and the simple act of the dentist asking about the AWDD patient's day. Small gestures on the part of the dental team can have a significant impact on the experience of the AWDD.

The parents talked positively of special accommodations that had been made by the office to accommodate the challenging needs of their dependent child. Examples of accommodation included scheduling an early appointment when there were no other patients in the waiting room or allowing time for the AWDD patients to spend time familiarizing themselves to the dental equipment. These gestures of empathy and caring helped build trust, enhance communication and develop respect between the dental team, the parents and the AWDD.

The domains that were obtained from the discussions of the participants have some similarities and some differences with the five A's of access by Penchansky [19]. The domains of financial issues and wait times are similar to two A's of availability and affordability and the domains of communication, respect and trust are related to the characteristics of acceptability. We found that the domain of transitional services did not quite fit within the confines of the Penchansky model and while we found examples of accommodation within the domain of positive experience, this domain also could not fit neatly within the five A's. As such we feel that the seven domian that we have presented here are a better representation of the particular experiences that AWDD have while accessing dental care in British Columbia and can be used to better identify barriers of access.

5.1 Limitations

Of course our research had limitations. One limitation may have been the interaction of the student researcher and the participants prior to the focus groups. These sessions helped to establish rapport and a level of comfort with potential participants. However, these interactions may have introduced bias, as the participants were aware that the researcher was a dental professional. This knowledge may have caused some participants to alter their comments in an effort to not upset or offend. However, all participants were informed that open discussion was encouraged and that complete confidentiality would be maintained. As the group discussion leader, the personal biases and idiosyncrasies of the student researcher may have also been a factor. The student researcher has had a

number of years experience working with developmentally disabled patients and has had a relationship with the AWDD community through volunteer work. To manage personal biases the student researcher attempted to not discuss his personal feelings on the issues as to not sway the group in any particular direction.

Another concern was our initial decision to use Penchansky's five domains of access: affordability, availability, accessibility, accommodation and acceptability [19] to guide the data analysis. Although an open-coding format was adopted later when we feared the framework would be too restrictive, our early reliance on these preconceived domains may have biased the analysis. Revisiting the coding process and using an open coding process helped to manage this concern.

Our venues for recruitment may also have affected the outcomes. Due to the difficulty in recruiting participants for a project of this nature, it was imperative to involve AWDD service organizations and support groups. As such, all of the participants were members of pre-existing self-advocacy and parent/caregiver support groups. This meant that these individuals might have been more likely to be interested in discussing and expressing the issues that they felt are important to the AWDD community concerning its relationship to the dental field. Although this fact helped in fostering interaction in the focus groups, it may have also affected the types of discussion that were conducted.

The reliability of the self-advocate responses was also an issue discussed by the research team prior to the focus group sessions. It should be noted that previous literature regarding reliability eyewitness memory of children with moderate intellectual disability has shown that reliability is, indeed, diminished [121]. However as this is a project focused on experiences from the perspective of AWDD community members and parent caregivers, it would not have been appropriate or even expected to validate the stories related by participants. Their words reflected their memory of the experiences and were interpreted as such.

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5.2 Conclusions

To our knowledge this is the first qualitative study, which looks at the experiences of AWDD and their families in accessing dental care in British Columbia. Our study identified domains that represent the experiences of access and quality of the dental care experience.

- Access to a care provider did not equate to satisfaction with quality of experience. The majority of participants had a dentist but many had concerns about the quality of their dental experience.

- Domains related to "system issues" arose from the data: <u>financial issues,</u> <u>transitional services</u> and <u>wait times</u> were possible barriers to access.

- Domains related to "provider issues" arose from the data: <u>communication,</u> <u>trust</u> and <u>respect</u> were crucial to the perceived quality of experience that AWDDs received.

- The domain of <u>positive experiences</u> demonstrated that simple steps to improve the experiences of AWDD in dental office setting could enhance perceived quality of experience.

- Advocacy by parents and families contributes to perceived quality of the dental experience of AWDD. Dentists and other care providers should respect and support this advocacy role.

5.3 Recommendations

The results of this study suggest that focus on establishing communication and trust with AWDD patients is key to a positive dental experience. One way for dental professionals to build skills in developing trust and enhancing communication would be to have time treating individuals with special needs in their training. Therefore we recommend that more effort be put into designing dental school curricula that emphasize dental care for special needs individuals. Dental faculties across the country can also attempt to establish more specialty training or residency programs in the care of special needs patients.

Results also showed that AWDD have much to contribute to the discussion regarding access to dental care in British Columbia and that they value participating in the process for positive change. Therefore we recommend that practitioners who are interested in working with special needs individuals spend time interacting and volunteering with this population outside the confines of a dental office. These types of interactions allow for a change in paradigm where oral health care workers can be seen more as advocates rather than just service providers. The results of this project also showed that financial issues and long wait time continue to be a problem for access to dental care for AWDD. Therefor we recommend working with policy makers to try and reduce hospital wait times and improve governmental benefits programs.

This project was undertaken due to a "disconnect" observed between survey study results and anecdotal evidence from the AWDD community. As such we have attempted to present a more in depth look at the issues that AWDD and their families face in gaining access to dental care. It is our hope that the domains presented in this study will allow future researchers to construct improved survey questions to be able to better assess the barriers to access and quality of dental care. Future studies should also explore methods to improve the dental experiences of AWDD patients and their families.

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Appendix 1

UBC DENTISTRY | UBC THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form – Focus group with self-advocates

An exploration of access to dental care for adults with developmental disabilities

Principal Investigator: **Dr. Rosamund Harrison**

                        Department of Oral Health Sciences,

                        Faculty of Dentistry, University of British Columbia,

Co-Investigator(s):   Dr. Amin Salmasi

                        Department of Oral Health Sciences,
Faculty of Dentistry, University of British Columbia,
* This research is part of Amin Salmasi's graduate MSc thesis

Ms. Joan Rush
Faculty of Law, University of British Columbia,

Sponsor: BC Dental Association
Canadian Fund for Dental Education

Purpose: Adults with developmental disabilities sometimes have special experiences of going to the dentist and getting dental care. As a self-advocate, you may be able to increase our understanding of these experiences by taking part in this study.

Study Procedures: If you agree to take part in the study, you will be interviewed in a focus group with about 4-8 other self-advocates. The interview will be done by one of the investigators (AS). You will be asked to talk about your experiences at the dentist as well as what you like and what gives you trouble when you go to the dentist. The investigator will tape and transcribe the interviews. He will have an assistant who will take notes. A session will last about 1 hour and you are asked to attend 1 session. At the end of the study, a summary of the findings will be given to you and you can tell us what you think of the results.

Potential Risks: There are no known risks to this study.

Possible Benefits: The information that we gather will help us understand what it is like for you to go to a dentist for care of your teeth. The information may help to make dental services better for adults with developmental disabilities.

Your privacy: We ask everyone who takes part in a focus group not to say anything outside of the group about what was talked about in the group. However, we cannot control what people from the group do or say with the comments that they heard in the group. Your role in the focus group and your identity will be kept private and confidential. Your name and any other identification will be removed from the study documents. All tape recordings will be stored on a password protected computer and external network. All documents will have a code number, not a name, and will be stored in a locked filing cabinet. You will not be identified by name in reports from the study.

Who to contact about the study: Before you sign this form, please ask any questions that you have about the study. If you have more questions, contact Dr. Amin Salmasi .He will answer any of your questions before, during or after the study.

Contact about rights of research subjects: If you have concerns about how you were treated in this study, contact the Research Subject Information Line in the UBC Office of Research Services.

Consent: Being in this study is entirely up-to-you. You may refuse to be part of it or may stop being part of the study at any time without any risk to your future at this center.

Your signature below means that you agree to what is learned from the interviews being in articles, journals, books and teaching materials. Your signature below indicates that you have been given a copy of this consent form.

_____
Name of person consenting (please print)

Appendix 2

UBC DENTISTRY | UBC | THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form – Focus group care-givers/Family members

An exploration of access to dental care for adults with developmental disabilities
Principal Investigator: Dr. Rosamund Harrison

Department of Oral Health Sciences,

Faculty of Dentistry, University of British Columbia,
Co-Investigator(s):   Dr. Amin Salmasi

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Sponsor: BC Dental Association
Canadian Fund for Dental Education

Purpose: Adults with developmental disabilities (AWDD) often have unique experiences going to the dentist and receiving dental care. Many AWDD require the assistance and advocacy of caregivers, parents or other family members to access dental treatment. As a caregiver or family member, we want to hear about your experience enabling the AWDD who you care for and support to receive dental services.

Study Procedures: If you agree to take part, you will be interviewed in a focus group with about 4-8 other care-givers/family members. The focus group will be led by one of the investigators (AS). You will be asked to talk about your experiences enabling dental care for the AWDD in your care. The investigator will tape and transcribe the interviews.

Potential Risks: There are no known risks to this study.

Possible Benefits: The information that we gather will help us understand the experiences of AWDD accessing dental care. The information may help to improve dental services for adults with developmental disabilities.

Your privacy: We ask everyone who takes part in a focus group not to say anything outside of the group about what was talked about in the group. However, we cannot control what people from the group do or say with the comments that they heard in the group. Your role in the focus group and your identity will be kept private and confidential. Your name and any other identification will be removed from the study documents. All tape recordings will be stored on a password protected computer and external network. All documents will have a code number, not a name, and will be stored in a locked filing cabinet.

Who to contact about the study: Before you sign this form, please ask any questions that you have about the study. If you have more questions, contact Dr. Amin Salmasi .

Contact about rights of research subjects: If you have concerns about how you were treated in this study, contact the Research Subject Information Line in the UBC Office of Research Services.

Consent: Being in this study is entirely up-to-you. You may refuse to be part of it or may stop being part of the study at any time without any risk to your future or that of the AWDD in your care at this center.

Your signature below means that you agree to what is learned from the interviews being in articles, journals, and books and teaching materials. Your signature below indicates that you have been given a copy of this consent form.

_____
Name of person consenting (please print)

_____

Appendix 3

Focus group guide:

1. Let's talk about the last time that you visited a dentist:
    a. What work was done
    b. How did it go?
    c. What about taking any medicine before your appointment to make you more relaxed; tell me what you remember.
2. I would like to know more about the dental office that you visit:
    a. Why do you go to this dentist?
    b. Tell me why you like or do not like this dentist that you go to.
    c. What can you tell me about the other people who work there?
3. Have you ever had a problem with your mouth e.g. a loose tooth or a toothache, has this ever caused you to miss any work or school or something that you wanted to do, e.g. go shopping. Tell me what you remember about this.
4. Did you ever need to go to a dentist and were not able to go? Why were you not able to get to see a dentist?
5. Some of you may have had to go to a hospital for dental care or needed to be put to sleep?
    a. Tell me about it.
    b. Tell me what you remember about waiting for your appointment? Long time? Short time?
6. Let's talk about the way your teeth look. Would you like something to be done to make them look better?
7. Is there any other thing you would like to tell me about your experience with dentists?
    a. What could be better?
8. Did you ever need a general anesthetic for dental treatment, that is, did you ever need to be put to sleep to get your teeth fixed?
9. Do you like the way your teeth look?

Appendix 4

1. Let's talk about the last time that you visited a dentist:
   How did you find the dentist? How did you get there?
   a. What work was done?
   b. How did it go?
   c. How often do you go to a dentist?
2. Have you ever had a problem with your mouth e.g. a loose tooth or a toothache, has this ever caused you to miss any work or school or something that you wanted to do, e.g. go shopping. Tell me what you remember about this.
3. Did you ever need to go to a dentist and were not able to go? Why were you not able to get to see a dentist?
4. Some of you may have had to go to a hospital for dental care or needed to be put to sleep?
   a. Tell me what you remember about waiting for your appointment? Long time? Short time? Did you have any problems while you were waiting?
   b. Why did you have to go to the hospital? Was your dentist unable to treat you?
5. I would like to know more about the dental office that you visit:
   a. Why do you go to this dentist?
   b. Tell me why you like or do not like this dentist that you go to.
   c. What can you tell me about the other people who work there?
6. Is there any other thing you would like to tell me about your dental care that you would like to have?
   a. What could be better?

Appendix 5

Focus Group Guide (CG/FM)

Amin Salmasi

1) Let's talk about the last time you accompanied your family-member or client to the dentist:

    a.   How did you find this dentist?

    b.   How did you travel there?

    c.   Were you in the treatment room or the waiting room during treatment?

    d.   Tell me what happened at the appointment and how you think the appointment went.

2) I would like to know more about the dental office that your client/family member visits:

    a.   Why do you go to this particular dentist? Or in other words, tell me why you like or do not like this dentist.

    b.   What can you tell me about the other staff who work at this office? Are they helpful in any particular way?

3) Have you ever had problems or challenges getting dental treatment for your family member/client? Tell me about the "problems" or challenges, how you solved them and who helped you solve them.

4) Tell me about the dental benefits of your family member/client.

5) Often adults with a developmental disability have to go to a hospital for dental care and/or need a general anesthetic so treatment cans be done safely.

    a.   Have you ever had to accompany your client/family member to this kind of appointment? If so, tell me what you remember about the experience.

    b.   How long did you have to wait for your family member/client to get the hospital appointment?

    c.   Tell me about any problems such as pain or trouble eating or sleeping while your client/family member waited for treatment?

6) Is there anything else that you would like to tell me about dental services for the family member or client who you support? What could be better?

Appendix 6

Questionnaire

Focus groups: self-advocate clients

Pre-focus group written questionnaire for each participant: demographics and dental health habits:

1- How old are you?
2- What is your disability?
3- What is your living situation?
4- How do you look after your own teeth and mouth at home?
   a. Use a toothbrush?
   b. Use toothpaste?
   c. Use dental floss?
5- Do you have a dentist?
6- How often do you visit the dentist?
7- How do you pay for dental work?
8- How do you get to your dentist?
9- How long does it take to get there?
10- Have you ever had a toothache?
11- Have you ever had to go to a hospital for dental care?
12- Did you ever need a general anesthetic for dental treatment (did you ever need to be put to sleep)?
13- Do you like the way your teeth look?