

**DENTAL CARE BEYOND BC CHILDREN'S HOSPITAL: PERSPECTIVES ON THE  
TRANSITION EXPERIENCE FOR YOUNG ADULTS WITH SPECIAL HEALTH  
CARE NEEDS**

by

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## **Abstract**

**Objectives:** To determine the extent to which young adults with special health care needs (YASHCN) who transitioned from care at BC Children’s Hospital Department of Dentistry (BCCH-DD) with/without the help of their caregivers were successful and satisfied in establishing a dental home and, to understand this transition process from the perspective of the dentists who care for them.

**Methods:** This cross-sectional study sampled two populations: YASHCN or their caregiver and dental providers known to care for persons with disabilities (PWD). **YASHCN:** Eligible subjects (n=80) born 1996 or earlier and discharged from care at BCCH-DD were identified. Demographic variables and medical diagnosis were collected from dental records. Subjects were surveyed by telephone to determine the accessibility, satisfaction, and barriers to dental care services. **Dentists:** Dentists identified as providers (n=11) for PWD were surveyed to collect practice demographics, education, and knowledge related to treatment of PWD. Univariate and bivariate analysis, and thematic description interpreted the data.

**Results:** **YASHCN:** forty subjects (50%) consented to participate in the telephone survey. The majority of YASHCN reported good/excellent oral health (57%), had seen a dentist in the last 12 months (70%), felt they had received what was needed (68%), and were satisfied/somewhat satisfied with the care they received (75%). Medical complexity, lack of awareness about dental needs and issues related to the transition process (poor communication, extended wait time for adult facility uptake) were reported as barriers. **Dentists:** Eight dentists (72%) participated in the survey. Patient cooperation, age, and severity of medical condition influenced the dentists’ decision to treat PWDs. Dentists confirmed YASHCN’s reported access difficulties and made

recommendations to address personal (behavior, age), family (caregiver involvement) and system level (insurance, hospital/anesthesia access) issues.

**Conclusions:** The majority of YASHCN/caregivers expressed satisfaction with their present dental status and dental care access. Their concerns, along with the recommendations of dental providers, should be considered in the refinement of the transition experience from BCCH-DD to adult care settings and also used to further advocate for dental care access for PWD of all ages.

## **Lay Summary**

Special needs youth in BC require access to dental care as part of their health care services. We know little about their transition experience from child-centered to adult-centered dental care. Therefore, we asked special needs youth (or their parents) if they were able to see a dentist after leaving BCCH, and their satisfaction with their current dentist. We also asked if they felt that they had received the care they needed from the new dentist. Additionally, we asked dentists what they thought about this issue and what suggestions they had to improve the transition process and dental care that special needs adults receive. We found that the majority of special needs youth reported good access to dental care and they were satisfied, however, they had some concerns. Dentists concurred with these concerns and also provided several recommendations to improve the dental transition experience of special needs youth in BC.

## **Preface**

Identification and design of this research project were by the co-investigator MA under the direction of his research supervisors, Dr. Karen Campbell, Dr. Rosamund Harrison and Dr. Mario Brondani. All aspects of the data collection and the analysis of the data were conducted by the co-investigator MA with the guidance of his supervisory committee. Regular committee meetings were held with the supervisory committee.

The University of British Columbia/Children's & Women's Health Centre of BC Research Ethics Board gave ethics approval (CW15-0184 / H15-01324). 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 12 January, 2015.

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## List of Abbreviations

|         |  |
|---------|--|
| AAPD    | American Academy of Pediatric Dentistry              |
| AGD     | Advanced general dentistry                           |
| BCCH-DD | BC Children’s Hospital Department of Dentistry       |
| BCDA    | British Columbia Dental Association                  |
| CSHCN   | Children with special health care needs              |
| GA      | General anesthesia                                   |
| GPR     | General practice residency                           |
| MSDSI   | Ministry of Social Development and Social Innovation |
| TRAC    | Taking Responsibility for Adolescent Care            |
| OR      | Operating room                                       |
| PWD     | Persons with disabilities                            |
| VGH-DD  | Vancouver General Hospital Department of Dentistry   |
| YASHCN  | Young adult with special health care needs           |

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## **Dedication**

I dedicate my thesis work to my exceptional family. A special feeling of gratitude to my loving parents whose words of encouragement and support always ring in my ears. My patient spouse Amani, my beautiful daughter Kendah, my brothers Abdullah and Amro and my sisters Hana, Haifa, Hanouf, Hanadi, Hoton and Jana.

## **Chapter 1: Introduction**

### **1.1 Definitions**

#### **1.1.1 Young Adults with Special Health Care Needs (YASHCN)**

There is no standardized or consistent definition that would apply to the young adult with special health care needs. The BC Ministry of Child and Family Development has defined these children and youth as “those up to 19 years of age who require significant additional educational, medical/health and social/environmental support — beyond that required by children in general — to enhance or improve their health, development, learning, quality of life, participation and community inclusion”(1). The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau’s provides a similar definition: “...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services ... beyond that required by children generally”(2). The World Health Organization defines disability as “any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner within the range considered normal for a human being” (3). Many other definitions are also reported in the literature (4–6). For the purpose of this study, the BC Ministry of Child and Family Development’s definition will be used to describe our sample of YASHCN.

Moreover, the “YASHCN/caregiver” phrase, which will be used repeatedly throughout the thesis, means that the respondent was either/or the YASHCN or their caregiver.

#### **1.1.2 Access to care**

Several definitions of the term “access to care” can be found in the literature (7,8). Aday and Andersen suggested that access can be described as “the potential or the actual entry of a

given individual or population group into the health care system”(9). Access to care has been defined by the U.S. Department of Health and Human Services as “the timely use of personal health services to achieve the best health outcomes that demands three distinct steps: 1) Gaining entry into the health care system. 2) Getting access to sites of care where patients can receive needed services. 3) Finding providers who meet the needs of individual patients and with whom patients can develop a relationship based on mutual communication and trust” (10).

## **1.2 Epidemiology of YASHCN in Canada and British Columbia:**

According to the Canadian-based 2006 Participation and Activity Limitation Survey (PALS), 14.3% of the total population had some sort of disability, which was an increase of 1.6% from the 2001 PALS results. Moreover, in both surveys, nearly 95% of those with disabilities were aged 15 years and over. Specifically, 15.9% of BC’s population, or approximately 640,000 people, had some form of disability. This percentage was an increase from 13.9% in the 2001 report (11). More recently, the 2012 Canadian Survey on Disability (CSD) revealed that 13.7% of the total adult population in Canada reported being disabled, with one out of four persons classified as having a very severe disability (12). Unfortunately, the results from this last survey cannot be compared with the previous results from the PALS because the former used a new sampling technique and thus the definition of ‘disability’ differed.

Recent data from the 2015-2016 British Columbia Ministry of Education estimated that about 56,286, or 10.2%, of the 553,378 school-aged children enrolled in the public education system had some form of special health care need. The Ministry’s categories for children with special health care needs (CSHCN) included the following: physically dependent, autism spectrum disorder, deaf/blind, intensive behavior interventions/severe mental illness, moderate to

profound intellectual disability, mild intellectual disability, physical disability/chronic health impairment, gifted, visual impairment, learning disability, deaf or hard of hearing, moderate behavior support/mental illness. (12)

### **1.3 Access of YASHCN to dental care**

Studies from a number of countries have shown inconsistent results regarding the degree of difficulty accessing dental care experienced by various special needs populations. The degree of difficulty reported ranges from 25 to 50%, likely due to the differing definitions surrounding “access” used (14–18).

In a 2004 study investigating access and possible barriers to dental care of children with special health care needs, 714 parents of CSHCN in Alabama, USA were surveyed to assess their opinions on this issue. The investigators found that 35% of the sample experienced some problems finding a dentist willing to treat their children (14). The primary barriers to seeking dental care included low reimbursement rates of Medicaid insurance (US public insurance), poor oral health requiring substantial commitment to treatment, and a shortage of dentists trained to treat CSHCN (14).

Another study was conducted to evaluate the availability of dental care to developmentally disabled CSHCN residing in 37 north central Florida group homes. The study concluded that almost 1 in 2 caretakers had faced difficulty in locating a dentist willing to provide comprehensive dental care for their CSHCN (16). Similar to the previous mentioned study, the dentists were unwilling to provide services to developmentally disabled individuals for a variety of reasons, including insurance issues (low reimbursement rates), inadequate training in the care of CSHCN, lack of cooperation of CSHCN, facilities not equipped to treat special needs patients, and being too busy with other patients (16).



A survey of 86 parents of cerebral palsy patients who attended the New Farm Spastic Centre in Brisbane Australia found that 25% of the patients had difficulties accessing dental care services. It is interesting that unlike North American studies, where the deficiencies in the healthcare system posed as the key barrier, the Australian study found that difficulties outside the dental clinic including transportation, lack of wheelchair-accessible dental clinics, and the level of severity of cerebral palsy were the barriers to access dental care (15).

In Canada specifically, little is known about access to dental care for young adults with special health care needs, and even less is known about access to dental care for this population in British Columbia. An Ontario survey by Koneru and Sigal in 2009 found that 3 out of 4 individuals with a developmental disability reported being able to access dental services (19). However, this finding may have been biased by the sampling method used in the study that was more focused on residents within the Greater Toronto area who might have more suitable dental facilities and better transportation and other supportive networks. Also, the study was biased toward Down Syndrome subjects whose recruitment was disproportionately supported by their community support group. Despite these shortcomings, the surveys determined that poor cooperation with treatment, fear of the dentist, cost of treatment and transportation difficulties remained common barriers to accessing dental care.

A novel qualitative investigation conducted recently in BC found that caregivers of PWD reported financial challenges and wait times for treatment as main barriers for BC families seeking care for their PWD (20). This study also revealed that transition from pediatric to adult medical and dental care settings was not supported by any formal process. Consequently, PWD caregivers tended to rely on networking with family/caregiver support groups to locate dentists willing to provide care. (20).

In summary, it appears that throughout North America and beyond, individuals with special health care needs have reported commonalities in barriers to receiving dental care, such as inadequate insurance, low family income, cost of treatment, transportation, their medical complexity, fear of dentists, and a shortage of adequately trained dental providers (21–30).

#### **1.4 Access to dental care: dentists' perspective**

Individuals identified as having special health care needs may present with a wide range of medical and intellectual disabilities that complicate their dental management. Regardless of whether dental treatment for YASHCN or PWD should be managed within or outside the hospital setting, the dentist's training, knowledge and willingness to provide treatment play important roles in the equation of the accessibility of any PWD to dental care. Previous studies found that the training of dental and postgraduate general dentistry students affected the special needs population's access to dental care. In 2004, a cross-sectional study was conducted to evaluate how prepared dental students in U.S. dental schools were to treat people with mental retardation [*sic*] and whether the amount of preparation affected their willingness to see those patients. The study sampled 295 dental students from five dental schools. The investigators found that almost half of the students had no clinical training in treating individuals with mental retardation [*sic*] and two-thirds of them reported having 'little' to 'no' confidence in providing care to these patients (29).

A cross-sectional study on 1,251 dentists using data from the 2001 National Survey of General Dentists was conducted to examine the care of CSHCN. They found that only one in 10 general dentists had seen CSHCN "often" or "so often". Seventy percent of the surveyed dentists reported that they "rarely" or "never" treated patients with SHCN. Further, only 25% of them

had any practical experience in treating CSHCN during dental school. The survey also revealed that there was no difference in willingness to treat CSHCN between general practitioners who had postgraduate general dentistry training and general practitioners who did not (21). The lack of didactic and clinical components that focus on individuals with special health care needs during dental and post-graduate education programs may partially explain why many dental students and dentists are reluctant to treat CSHCN.

In 2016, a study surveyed 88 senior dental students from the faculty of dentistry at the University of Toronto, before and after providing dental care to PWD in order to evaluate their expectations and experiences. Most of the students reported feeling more comfortable after providing dental care to PWD than before having the experience (49% and 28% respectively). The study suggests that exposing dental students to such a clinical experience enhances their comfort in treating PWD (31). Indeed, it would be of interest to re-sample those dental students in longitudinally to see if they indeed chose to treat PWD in their day-to-day practice.

The responsibility for managing dental care for PWD, beyond just younger children with SHCN, may often be shouldered by pediatric dentists, who by virtue of their training may have the behaviour management skills, disposition and access to facilities to address the dental care needs of this population. This is evidenced by an American Academy of Pediatric Dentistry (AAPD) member survey that reported 95 percent of the survey respondents routinely treated patients with special health care needs in their practices (32). However, the relative small number of pediatric dentists compared to general dentists suggests that more general dentists may need to assume some of this burden. Also as CSHCN mature into adults, their dental needs extend into the realm of adult dentistry and well beyond the scope of pediatric dentistry. This also confirms that more involvement by general dentists is desirable to address the needs of YASCHN and

PWD. Given this realm of adult dentistry often may involve multiple dental specialties, the knowledgeable general dentist may be best suited to “quarterback” the care (33).

According to the College of Dental Surgeons in British Columbia (CDSBC) and the British Columbia Dental Association (BCDA), there are 3256 general practice dentists (GPD) in British Columbia, and nearly 25% of these are practicing in the city of Vancouver. However, only 1 out of 20 GPD in Vancouver listed themselves on the BCDA website as practitioners accepting new patients who have medical, mental or physical special needs. Seeking the perspective of BC-based dentists and specialists who are known to actively accept and provide on-going care for patients with special health care needs would be valuable to gain a better understanding of issues pertinent to YASHCN’s access to dental care services in BC.

### **1.5 Transition from pediatric to adult-centered care**

Transition of care has been defined as the “purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care” (34). It has also been defined as “the movement of a patient from one setting of care (hospital, ambulatory primary care practice, ambulatory specialty care practice, long-term care, home health, rehabilitation facility) to another” (35)(36). Although the transition of care is not an experience limited to YASHCN, it can be a particularly challenging step for them as they are at risk of facing multiple difficulties in comparison to healthy non-YASHCN youth, reduced quality of life (QOL), impaired social functioning, anxiety disorders, depression, and suicidal ideation (37–39). Moreover, YASHCN are more likely than their healthy peers to be involved in risky behaviours such as tobacco, alcohol and illicit drug use (40). Therefore, the transition of care for YASHCN is often challenging and significantly burdening both YASHCN and their parents/caregivers. In

Montreal, QC, a group of researchers interviewed 17 parents of young adults with chronic neurologic and intellectual impairment to understand their perceptions regarding the transition process of their charges. Overall, parents experienced a sense of loss, fear and uncertainty during their YASHCN's transition process. They encountered issues with health care system coordination and noted an absence of resources to guide them through the process (41). These findings indicate a need for both family and health care providers to come together to establish an individualized and coordinated plan for care transitions.

In 2010, 1,686 pediatric dentists, who were randomly selected from the AAPD membership database were surveyed regarding their process for transitioning adolescent patients with and without special health care needs (SHCNs) to adult care. The majority of pediatric dentists reported assisting YASHCN with their transitions to adult care in various ways, while the most frequently reported barrier to this transition was the lack of available dentists who were willing to accept YASHCN as new patients (42). Another group of researchers interviewed a total of 13 general and pediatric dentists to understand their perception about dental care transition of YASHCN. They found that, from the dentists' perspective, the main barriers to the transition process were the low rates of dental reimbursement and yet again the shortage of dentists qualified or willing to manage YASHCN (43). These same investigators conducted a parallel study to understand the transition issue from the perspective of YASHCN and their caregivers. Particularly, caregivers of young adults with complex medical conditions presented some concerns about moving their youth to an adult-focused facility. Some YASHCN stated that they missed the "fun" and "kid-friendly" ambiance of the pediatric dental office and their long-standing relationship with pediatric dentists who knew them and understood the barriers to transition posed by their conditions. Moreover, type of insurance and difficulty finding a general

dentist sufficiently knowledgeable about their health conditions were reported as barriers to successful transition (44).

In recognition of the importance of ensuring that YASCHN transition to adult dental care in a supported and coordinated manner, the AAPD has developed and recently updated their policy statement on transition for individuals with SHCN (33). Included in this policy statement, among other things, was the encouragement of partnerships to prepare general dentists to be primary care providers; suggestion to develop alternative care delivery arrangements to further enhance existing care provided through private practices; and placing emphasis on educating undergraduate dental students on the treatment of individuals with SHCN.

To date, no study has assessed the transition process of YASHCN from pediatric to adult-centered dental care services in British Columbia. Anecdotally, some BC pediatric dentists tend to continue to see YASHCN into adulthood and provide the dental care needed. It is usually the pediatric dentist's decision to determine when transfer to an adult dental care facility is needed. For instance, this may be necessary if the YASHCN's medical condition has worsened, or they become physically difficult to safely manage in a pediatric dental setting.

## **1.6 Medical transition process at BCCH**

'ON TRAC' was developed a few years ago by Provincial Health Service Authority and BC Children's Hospital as a province-wide initiative to facilitate and support youth between 12 to 24 years old with chronic health conditions throughout their transition from pediatric to adult-centered health care services. ON TRAC works with both pediatric and adult medical health care providers, the youth with chronic or complex health conditions and their families. ON TRAC focuses on increasing awareness about transition issues; sharing resources, clinical guidelines

and toolkits; and arranging workshops and presentations for youth, families, and health care providers (45). Although this multi-faceted process may be well-intentioned, it remains unknown how well this has been adopted by the medical community or how it can be modified or used as a framework for dental transition, given the unique differences between the dental and medical resources and models of care.

### **1.7 Dental insurance coverage for YASHCN in BC**

The BC Ministry of Social Development and Social Innovation (MSDSI) offers limited dental benefits (such as restorations, extractions, and preventative services) up to \$1000 over two calendar years for adults with the Persons With Disabilities (PWD) designation. In addition, those adults may be eligible for an extra \$1000/year of dental treatment when dental treatment is performed under general anaesthesia or using intravenous sedation in a hospital or Provincial Health Services Authority (PHSA) approved private facility. Orthodontic treatment, crowns, and fixed or removable dentures are additional dental services offered to PWD under very limited and specific criteria. Only emergency dental treatment (e.g., extractions and abscesses drainage) can be done after the YASHCN has exceeded the Ministry's limit for dental coverage.<sup>1</sup>

### **1.8 BCCH-DD: Dental services for YASHCN**

BC Children's Hospital Department of Dentistry (BCCH-DD) provides comprehensive dental care for children and adolescents with special health care needs up to the age of 17 years. In some cases, the department will extend care into early adulthood as required by treatment

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<sup>1</sup> <http://www2.gov.bc.ca/gov/content/governments/policies-for-government/bcea-policy-and-procedure-manual/health-supplements-and-programs/dental-and-orthodontic-services>

needs or patient management needs. Typically, a ‘transition’ plan (to facilitate timing of all dental treatment needs) is established for each patient by his or her 16<sup>th</sup> birthday, so that they can be discharged from care in optimal dental health. However, currently there is no formal transition assistance to ensure that discharged patients find a dental home to meet their specific needs. When feasible, the department directs the family to investigate the possibility of integrating their young adult into a community-based dental office that provides such support. Examples include the ‘family dentist’ who is already caring for other members of the family; or perhaps a locally-practicing pediatric dentist who may be accepting new patients. Generally, the specialty training that a pediatric dentist receives would support the care of young adults with a variety of special health care needs. This includes behavioural management principles that approximate those needed for intellectually-challenged adults, and most graduate programs provide the didactic background on medical management of these adults. However, many YASHCN require additional medical management in a hospital setting because they have complicated medical conditions, or can only be treated under general anesthesia due to either co-morbidity or behavioral concerns. The only potential publicly-funded ‘dental home’ that currently exists for young adults with complex special health care needs is the Dentistry Department at Vancouver General Hospital (VGH-DD). In order to facilitate the transition to VGH-DD and other practices, BCCH-DD provides a written referral for YASHCN that includes a brief summary of the relevant medical/dental history and information about the status of oral health. Once this referral has been sent, the BCCH-DD patient file is considered closed. However, little is known about the actual transition experience once this referral process is complete – in fact, in some cases it is not known whether the transition even actually occurs. Further, little is also known about the ease or



difficulty with which the YASHCN adapts to the new dental home and how satisfied YASCHCN and/or their caregivers are with it.

### **1.9 “Access to Dental Care” as a research theme**

In recent years, a number of research projects have been undertaken by UBC Dentistry addressing the “Access to Dental Care” theme, investigating different aspects of the issue in a provincial context. Sample populations selected for study within this theme included caregivers of CSHCN actively under care at BCCH-DD, adults with developmental disabilities and dental providers across BC’s communities. These previous studies have helped to identify and better understand the overarching issues for BC patients with special health care needs, from a variety of perspectives.

The first study in 2013 sought to identify issues for those families with children with SHCN in their journey to access dental services that ultimately led them to BC Children’s Hospital. It was found that the complexity of the child’s medical status, the referring dentists’ inability or unwillingness to provide care and financial difficulties were identified by parents as barriers to access dental care. Many caregivers also felt that publicly-funded tertiary-level care facilities such as BCCH were overall better equipped to provide dental care to their CSHCN (46).

A second investigation in 2014 aimed to evaluate the experiences of adults with developmental disabilities (AWDD) accessing dental services in BC’s Lower Mainland. The study identified trust, respect and communication from the dental provider as integral factors in the quality of the dental experience for AWDDs and their caregivers. The study also found that financial issues and extended wait times to receive dental care were the main barriers AWDD

faced. For the transition from pediatric to adult dental care there was no clear pathway, and only those AWDD with an established “networking” were they successful in navigating their way to a new dental home (20).

In 2015 a study investigated the perceptions of the BC dental community with respect to their willingness and comfort in providing treatment for children with certain categories of special health care needs. It was determined that both scientific and practical uncertainty related to the issues of CSHCN affected dentists’ ability to provide dental care to this population. Dentists expressed concern about their limited access to general anesthesia for the provision of care, and feared negative medical outcomes for taking on more complex special needs patients because of their inadequate training in the area of CSHCN management. Many also felt that reimbursement for the extra time and responsibility needed to care for these children was inadequate (47).

These previous studies on the “Access to Dental Care” theme for BC children and adults with special health care needs provided valuable insight about the barriers in the journey to receive care, the attributes desired by those receiving the care from their dental provider, and the professional uncertainty and challenges on the part of the dental providers delivering the care to these special pediatric patients. However, they do not expand our understanding on the potential issues that seem to exist in this process and if the care in the new dental home is perceived as satisfactory.

### **1.10 Impetus for further research**

Similar to other jurisdictions, a number of concerns have been recently raised in BC, particularly about the access of YASHCN to regular dental care. These concerns have been

expressed publicly and on a number of occasions, in the headlines of local newspapers (48–50). The issues of access that were reported included difficulty finding a dentist; deficient provincial government dental coverage for the disabled; an inadequate effort by the provincial dental college to maintain equality of access to dental care; inadequate preparation of dental graduates to treat disabled adults, and the lack of a dental specialty focused specifically on the care of individuals with special health care needs. In an effort to further explore and expand our knowledge regarding access to care, the transition from pediatric to adult dental care services for those young adults with special health care needs should be investigated in more detail, in the following areas:

1. The accessibility to dental care services experienced by BC-residing YASHCN after being discharged from BCCH-DD.
2. The scope and nature of services that YASHCN receive customarily from BC dental providers, and their level of satisfaction with this care.
3. The characteristics of dentists who accept and treat YASHCN or PWD in BC.

### **1.11 Research objectives**

1. To determine if YASCHN (with/without the help of their caregiver) were successful in establishing a sustainable dental home following transition from BCCH-DD, and if successful, to rate their satisfaction with the new dental home.
2. To better recognize the challenges and enabling factors in the transition process.
3. To assess the ‘post-transition’ dental status of a sample of YASCHN using subjective and objective measures.

4. To characterize the dental providers who care for YASCHN in their practices, and to explore their perspective on providing this care.

## **Chapter 2: Methods**

### **2.1 Study design**

BCCH-DD aims to deliver comprehensive, preventative and therapeutic oral health diagnosis and treatment as well as consultative expertise for infants, medically compromised children, and adolescents up to the age of 17. Approximately 50 to 80 patients per year are transitioned from BCCH-DD to VGH-DD or a community dentist known to accept PWD. This cross-sectional study targeted two different types of participants in order to collect the information needed to answer the research questions: YASHCN (or their parents/caregivers) and dental care providers.

For part 1 of the study, pre-tested questionnaires with closed and open-ended questions were administered to YASHCN or their parents/caregivers. A dental examination was also offered to those participants who were willing to complete another more detailed and pre-tested questionnaire. For part 2 of the study, a questionnaire with closed and open-ended questions was administered to dental providers.

### **2.2 Study participants**

The study included YASCHN who were former BCCH-DD patients with birthdates up to and including 1996. These subjects had been discharged from BCCH-DD prior to January 1<sup>st</sup>, 2015, and were permanent residents or citizens of BC. Those YASHCN for whom it was impossible to gain consent were excluded from the study (i.e. foster care or group home clients). Moreover, subjects were selected only if their internal dental charts were still physically available in the storage area for BCCH-DD. Generally, inactivated dental charts are archived on-

site for a period of two years, but due to space limitations for on-site storage those beyond the two-year period of inactivation are archived in an off-site location. Retrieval of archived records from this location imposed a significant cost per chart that was not covered by the budget of the research project. Therefore, 208 archived dental charts readily available in our clinic or in local storage that had not yet been transferred off-site made up the sample pool. A computerized approach to simple random sampling was used to select our 80 subjects.

The second part of the study sampled dental care providers, and the website of the BC Dental Association (BCDA) was used to identify 146 general practice dentists and dental specialists in Metro Vancouver who were accepting new patients with special health care needs. However, upon contact, a number of those admitted that they actually did not care for YASHCN. Therefore, participants for the dental provider group were subsequently recruited by two main sources: 1) suggestions from discussion with research committee members who identified a number of dentists known to treat YASHCN or PWD, and 2) responses from the YASHCN or caregiver participants surveyed, which yielded names of dentists.

### **2.3 Sample size**

By virtue of the preliminary and exploratory nature of our study, the sample size for both parts of the study – YASHCN/caregiver and dental providers – was solely dependent on the number of subjects that were able to be recruited in the time period of study, i.e., November 2015 to July 2016. Therefore, no sample size calculation was done.

## **2.4 Data collection instruments**

Two main instruments were developed for the first part of the study, which targeted YASHCN/caregivers: an abbreviated “quick” survey to be answered over the phone, and a detailed survey to be answered in person, which had two versions (A - for the caregiver, and B, for the YASHCN). All surveys were pretested and validated.

The abbreviated survey consisted of five questions and was designed to briefly evaluate the accessibility, satisfaction levels and barriers pertinent to dental care services among the YASHCN subjects once contacted over the phone. The detailed survey was designed to investigate caregiver (version A) and/or patient (version B) demographics, identify the specific details of the subject’s special health care needs, types of dental benefits, access to/satisfaction with dental care, and barriers (if any) to dental care services. Lastly, data collection entailed a subjective assessment of YASHCN’s current dental needs. Both versions of the detailed surveys (A and B) contained similar questions, with an additional section should the respondent be the caregiver of the YASHCN. In the latter case respondents were asked about their relationship to the YASHCN, area of residence, education level, household income, and the number of dependents they support.

For the second part of the study, which targeted dental providers, a different survey instrument was designed and pretested, containing both closed and open-ended questions. Demographic information was collected in addition to information about the dental provider’s educational background, years since graduation, specialized training (if any), and practice location. Dental providers were asked to outline what dental services they offered, what proportion of their work week was typically allocated to persons with disabilities, what proportion of their patient caseload this population represented, and general “wait-times” for

treatment/preventive appointments for these patients. Further, dental providers were asked to give their perspective regarding past frustrations, successes and/or challenges they experienced in providing care for this population. Lastly, they were asked to provide any recommendations that, in their opinion, would improve/facilitate the transition and subsequent care for these patients.

## **2.5 Data collection process**

### **2.5.1 Part 1 – YASHCN**

For the first part of the study, which was directed toward YASHCN and their parents/caregivers, the following three steps (Figure 2-1) were followed:

1. An information package was mailed to all potential participants (letter of invitation + consent form) using Canada Post.
2. Following a waiting period of 2 weeks, potential participants had a follow up phone call by the co-investigator, MA, to ask if they wish to participate in the study. If the subject responded positively with verbal consent, the abbreviated “quick” survey (five questions, including one open-ended query) was administered regardless of whether the subject/caregiver reported that he or she has/does not have a dental health care provider. If the subject responded that they did not wish to participate, the call was terminated.
3. Following the “quick” survey, the participant/caregiver was asked if they wished to participate in the in-person component of the study (to be held at BCCH-DD). If they responded positively, an appointment was made for the participant (with the caregiver as required) and they were asked to bring the signed consent form they had been mailed with them. During the in-person appointment at BCCH-DD, another detailed survey was

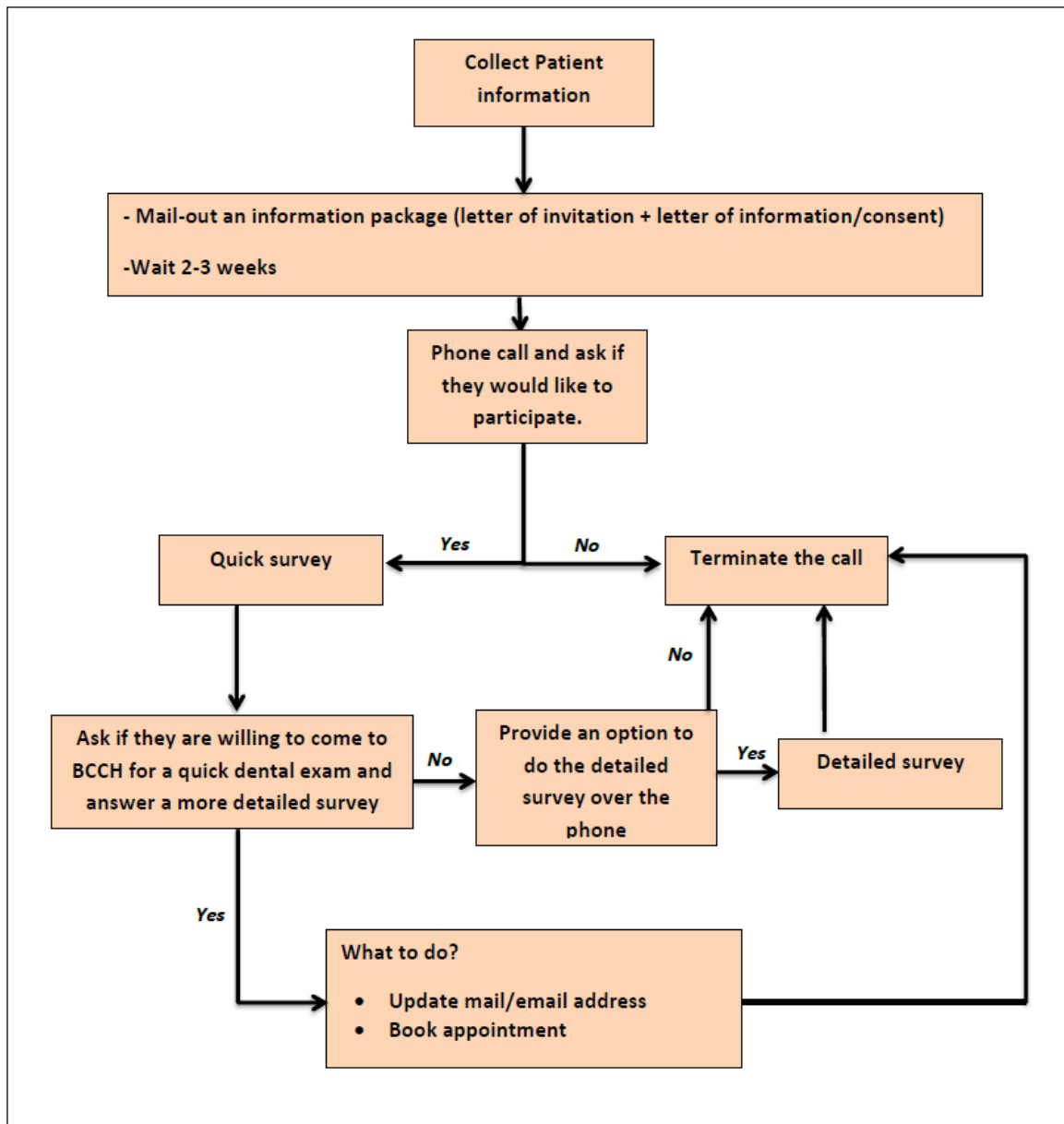


given to participants to fill out, one for the caregiver (version A) and one for the YASHCN (version B). Three survey questions were open-ended for an exploratory thematic analysis. The appointment was offered at no cost, with additional participant incentives for attendance (parking costs and oral health supplies). At this appointment, the co-investigator (MA) would complete the following:

- brief visual exam to assess overall oral health status, using mouth mirror and light source;
- recording of oral hygiene status, presence/absence of acute dental conditions, and level of participant co-operation;
- completion of the longer questionnaire for YASHCN or caregiver.

After the ‘quick survey’, participants were also given the option to have the detailed survey completed over the phone in case they did not want to come to BCCH (Figure 1). In this case, the detailed survey was completed under verbal consent only.

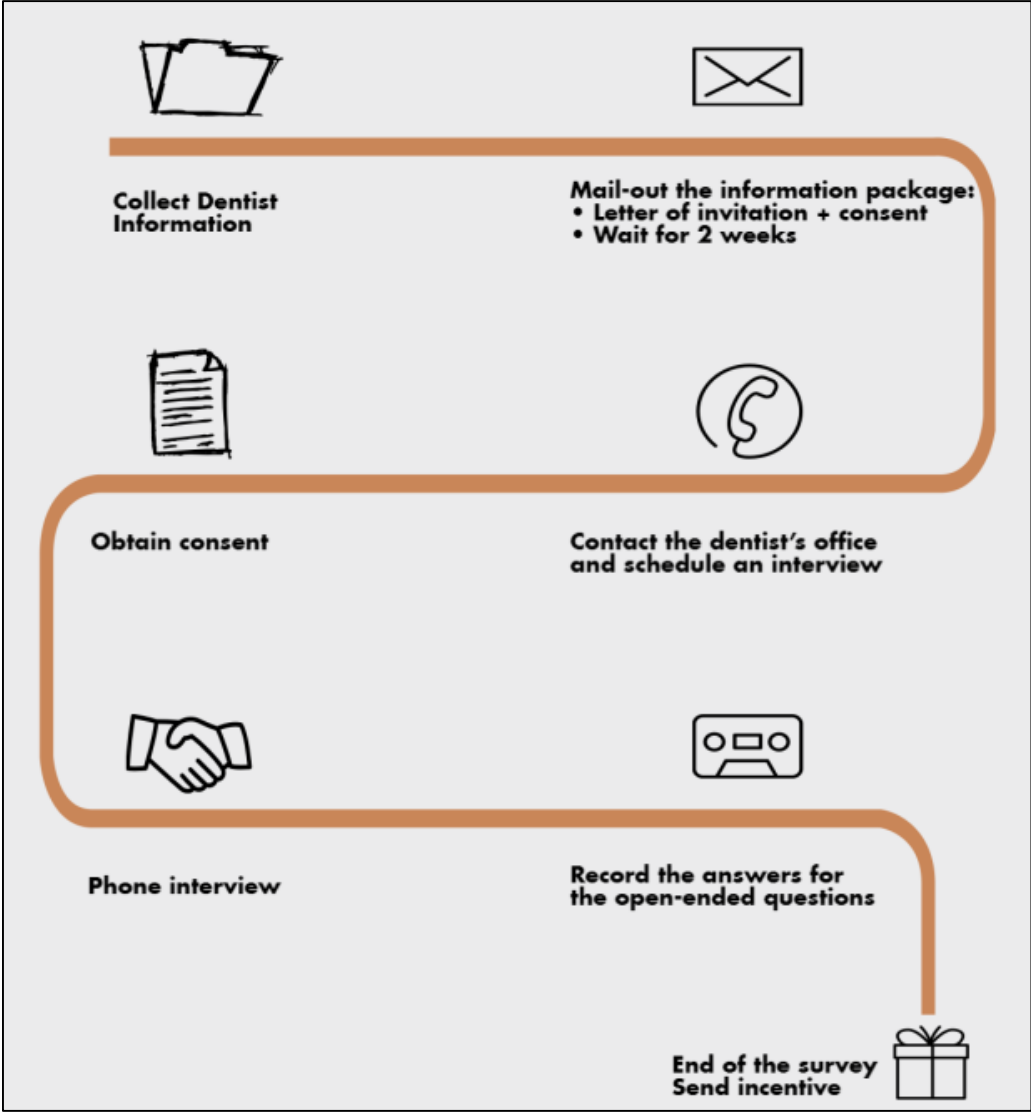
Figure 2-1 YASHCN recruitment flow chart



### **2.5.2 Part 2 - Dentists**

After the dental provider identification process was complete, an information package about the study (letter of invitation + consent form) was mailed out using Canada Post or, if email address was known through public website, by e-mail to dental providers who were potential participants (Figure 2.2). After a two-week waiting period, the co-investigator (MA) made phone/email contact with the potential participants to inquire if they wished to be part of this study. If the response was “no”, the call was terminated. If “yes”, the co-investigator set up an appointment for purposes of interviewing each consenting dental provider either in person or by phone. During the scheduled time, a pre-tested survey was administered in an interview format (“dentist survey”) to the selected participants. The survey was completed using two approaches, in-person and phone interviews, based on the preference, availability and the office location of the participating dentists. Three questions on the survey was in an open-ended format to allow an exploratory thematic analysis after being transcribed. Participants were thanked with a \$10 Starbucks coffee card.

Figure 2-2 Dentist recruitment flow chart



## **2.6 Statistical Analysis**

All analysis procedures for the quantitative data were done using SAS® version 9.2. (SAS Institute, Cary, NC, USA). The answers to the open-ended questions were transcribed, and separately coded and categorized by one committee member (RH) and the co-investigator (MA) until agreement on the codes and categories were reached.

### **2.6.1 Descriptive statistics**

Descriptive statistics for the YASHCN/caregivers and dental providers were used to characterize the study population. Frequency distributions of the YASHCN demographic variables including age, gender, number of medical conditions, type of medical condition, condition of oral health, availability of and accessibility to dental care, and satisfaction with the current dental care were measured. Furthermore, frequency distributions of the dental care provider's background education, specialized training, years since graduation and practice location were recorded.

### **2.6.2 Bivariate statistics**

Bivariate analyses were completed for some YASHCN variables to assess the potential relationship between the selected set of predictors (gender, number of medical conditions, type of medical condition, and time since discharge from BCCH-DD) with the following variables: oral condition, number of dental visits in the last 12 months, receiving the dental care that was needed, and satisfaction with dental care. Chi-square statistics and the Fisher Exact test were

used simultaneously in the bivariate analyses. However, the Fisher Exact test was found to be the best fit for the majority of the data set as it yielded a more conservative interpretation than Chi-square statistics.

## Chapter 3: Results

### 3.1 Part 1 –YASHCN

#### 3.1.1 Descriptive Analyses

Participants were recruited in three waves, in December 2015, February 2016 and March 2016. A total of eighty YASHCN were contacted to participate in the study. After four months of recruitment, forty subjects (50%) agreed to enroll in the study. Table 3-1 provides further detail about the three waves of YASHCN recruitment process, and individual's reasons for declining participation in the study.

**Table 3-1 YASHCN recruitment waves**

| Recruitment Wave                    | Dec 2015  | Feb 2016  | March 2016 | Total     |
|-------------------------------------|-----------|-----------|------------|-----------|
| # of surveys sent                   | <b>30</b> | <b>20</b> | <b>30</b>  | <b>80</b> |
| # of respondent                     | <b>14</b> | <b>12</b> | <b>14</b>  | <b>40</b> |
| Non-participating subjects: Details |           |           |            |           |
| Declined                            | <b>2</b>  | <b>2</b>  | <b>4</b>   | <b>8</b>  |
| Transferred to adult care facility  | <b>2</b>  | <b>1</b>  | <b>--</b>  | <b>3</b>  |
| Contact number out of service       | <b>4</b>  | <b>2</b>  | <b>4</b>   | <b>10</b> |
| No forwarding address               | <b>3</b>  | <b>--</b> | <b>2</b>   | <b>5</b>  |
| No answer when contacted by phone   | <b>5</b>  | <b>3</b>  | <b>6</b>   | <b>14</b> |
| <b>Response rate = 50%</b>          |           |           |            |           |

The study population under investigation consisted of YASHCN who were former active BCCH-DD patients with birthdates up to and including 1996 who had been discharged from

BCCH-DD prior to January 1<sup>st</sup>, 2015. Of the final sample (n=40), all were permanent residents or citizens of BC. Only three YASHCN responded to the survey themselves, the other thirty-seven participants were parents or caregivers of YASHCN.

About 55% of the study sample were males (n= 22). Subjects’ ages ranged from 18.2 to 24.3 years old, with mean age = 20.1 years (SD ± 1.7). Moreover, 52.5% of our participants had been discharged for a period less than 12 months prior to being recruited for the study. Over half (55%) of the study subjects had more than two medical conditions, while 28% had two medical conditions, and 17% had one medical condition as reported at the time of the interview. Thirty-two percent of the participants had “intellectual disability” listed in their medical chart (Table 3-2).

**Table 3-2 YASHCN descriptive variables**

| Variable  | N (%)          |          |                 |
|---|----------------|----------|-----------------|
| Gender  | Male           |          | Female          |
|   | 22 (55%)       |          | 18 (45%)        |
| Age (years)   | Mean + SD      |          | Range           |
|   | 20.1 ± 1.7     |          | 18.2 – 24.3     |
| Number of medical conditions  | 1              | 2        | More than 2     |
|   | 7 (17%)        | 11 (28%) | 22 (55%)        |
| Intellectual vs. solely physical disability   | Intellectual * |          | Solely physical |
|   | 14 (32%)       |          | 26 (68%)        |
| *some subjects in this group may have physical in addition to intellectual disability |                |          |                 |

**YASHCN 5-question “quick” survey**



The survey was composed of five questions that briefly evaluated the accessibility, satisfaction levels, and barriers pertinent to dental care services for the YASHCN subjects. The first 4 questions were closed-ended questions, and the last question in the survey was an open-ended question.

***Question 1: How would you describe the condition of her/his/your teeth? (Table 3-3).***

The YASHCN/caregiver was given the option of describing the condition of YASCHN's dental health on a scale from "poor" to "excellent". An "I don't know" option was provided for those who were uncertain of the answer. Nearly 1 in 5 (17%) YASHCN/caregivers described the condition of the teeth of the YASCHN as "Excellent" and another 40% as "Good". Of the remainder, "Fair" was reported by 30% and only a small percentage (5%) of the participants described the dental condition as "Poor". Eight percent were uncertain of their dental condition and responded "I Don't Know".

***Question 2: During the past 12 months, did she/he/you see a regular/family dentist?***

***(Table 3-3).***

The majority of YASHCN participants (70%) had seen a dentist in the 12 months preceding the time of the interview.

***Question 3: Did she/he/you receive the dental care that she/he/you felt was needed?***

***(Table 3-3).***

About two-thirds (67.5%) of the participants (YASHCN/caregivers) felt that they received the necessary dental care. In contrast, 22.5% of the sample felt the opposite – that they did not receive the dental care they needed. Four subjects (10%) answered “I don’t know”.

***Question 4: In general, how satisfied overall are you with her/his/your access to dental care? (Table 3-3).***

About half (47%) of our participants responded that they were “Very satisfied” with their access to dental care at the time of the survey, whereas 30% answered that they were “Somewhat satisfied”. Interestingly, 1 in 5 participants reported feeling “Somewhat unsatisfied”, and only 2 participants were “Very unsatisfied”.

***Question 5: Why did she/he/you not see a regular/family dentist during the past 12 months OR not get the dental care that he/she needed? (Table 3-3).***

This was the only open-ended question in the “quick” YASHCN survey. Therefore, the results from the question were categorized into major themes that reflected participants’ responses. The major themes that were repeatedly indicated by the YASHCN/caregiver were:

- **Medical status:**

Several families reported that the complexity of the YASHCN medical condition presented some difficulties in terms of accessing dental care. One mother of a subject with cerebral palsy stated: “*she is difficult to be seen in a regular dental clinic because of her condition*”. The mother of an autistic subject stated: “*he is not cooperative with our family doctor; he needs to be put under to get his teeth*”.

*fixed*". This comment referred to the fact that he required general anesthesia to have any dental treatment done.

- **Uncertainty about dental needs:**

A few parents reported that they didn't know the status of their YASHCN's dental needs. One father stated: *"I am not sure if his teeth are ok because we can't get in there"*, but added that *"he doesn't complain, so I don't think he has a problem with his teeth"*. Another mother commented that *"the last time he got checked was in your clinic"*, and then asked: *"when should we get him checked again?"*. Both parents were clearly uncertain of their YASHCN's dental needs, and therefore needed to be educated about those needs and the importance of meeting them.

- **Issues related to the transition process:**

Finding an appropriate dental care provider remains integral to the success of any transition process for YASCHN. Many caregivers reported that YASCHN had previously received their dental care at VGH-DD. Only a few were cooperative enough to be seen by their family dentist. Overall, only two caregivers reported that their YASCHN had experienced some issues when they were transitioned to adult dental care settings. These issues were mainly related to:

- Poor communication:

One father stated: *"I haven't been called by anyone, I called them (VGH) a couple of times before Christmas to book a check-up but no one picked up..."*.

- Long wait time for adult facility uptake:

Two parents reported that they have been waiting for almost one year for their YASHCN to be seen under GA at VGH. One mother reported: *“they saw him last year, and he is supposed to have the surgery this year but I don’t know when....”*.

### **YASHCN “detailed” survey**

As explained in the methods section, after subjects/caregivers completed the “quick” survey, they were asked if they wished to participate in the in-person component of the study at BCCH-DD. If they responded positively, an appointment was made for them. Unfortunately, only two subjects of the entire sample agreed to proceed with this part of the study. Given this small number, it was decided to set aside this focus to put more effort toward recruitment for the quick survey. Therefore, no information was collected using the “detailed survey”.

**Table 3-3 YASHCN/caregiver responses to the quick survey**

| Question   | Response N (%)  |                    |                      |              |              |
|--|---|--------------------|----------------------|--------------|--------------|
| Q.1: How would you describe the condition of her/his/your teeth?   | Excellent   | Good               | Fair                 | Poor         | I don't know |
|  | 7 (17%)   | 16 (40%)           | 12 (30%)             | 2 (5%)       | 3 (8%)       |
| Q. 2: During the past 12 months, did she/he/you see a regular/family dentist?  | Yes   |                    | No                   |              |              |
|  | 28 (70%)  |                    | 12 (30%)             |              |              |
| Q. 3: Did she/he/you receive the dental care that she/he/you felt was needed?  | Yes   | No                 |                      | I don't know |              |
|  | 27 (67.5%)  | 9 (22.5%)          |                      | 4 (10%)      |              |
| Q. 4: In general, how satisfied overall are you with her/his/your access to dental care?   | Very satisfied  | Somewhat satisfied | Somewhat unsatisfied | Unsatisfied  |              |
|  | 19 (47%)  | 12 (30%)           | 7 (18%)              | 2 (5%)       |              |
| Q. 5: Why did she/he/you not see a regular/family dentist during the past 12 months OR not get the dental care that he/she needed? | <ul style="list-style-type: none"> <li>◦ Medical status</li> <li>◦ Uncertainty about dental needs</li> <li>◦ Issues related to the transition process: <ul style="list-style-type: none"> <li>◦ Poor communication</li> <li>◦ Long wait time for adult facility uptake</li> </ul> </li> </ul> |                    |                      |              |              |

### **3.1.2 Bivariate Analyses**

The potential relationships between the selected set of predictors (gender, number of medical conditions, type of medical condition, and time since being discharged from BCCH-DD) and the following variables: oral condition, number of dental visits in the last 12 months, receiving the dental care that was needed, and satisfaction with dental care were analyzed with bivariate statistical tests.

Overall, subject gender, number of medical conditions and type of medical condition were found not to be significantly associated with YASHCN oral condition, number of dental visits in the last 12 months, receiving the dental care that was needed and satisfaction with dental care (p-values greater than 0.05) (Table 3-4). Additionally, time since being discharged from BCCH-DD (more or less than 12 months) was also not significantly associated with receiving the dental care that was needed and satisfaction with dental care (p-values greater than 0.05) (Table 3-4)

However, our analyses show that the time since YASHCN were discharged from BCCH-DD of YASHCN (more than or less than 12 months) was statistically significantly associated with their oral condition and number of dental visits in the last 12 months; p-values of 0.012 and 0.013 respectively. According to our results, the majority of YASHCN who were discharged less than 12 months prior to the interview described their oral condition as “Excellent” or “Good”. In contrast, YASHCN who were discharged from BCCH-DD more than 12 months prior to the interview tended to describe their oral condition as “Fair” or “Poor”. Additionally, the majority of YASHCN who were discharged from our BCCH-DD clinics less than 12 months prior to the interview usually did not report another dental visit since that time, while those who were

discharged more than 12 months prior the interview had successfully seen a new dentist. (Table 4)

**Table 3-4 Bivariate results of selected YASHCN variables**

| Variable                                       | Levels               | Gender |              | # of medical conditions |   |               | Time since discharge |       |
|--|----------------------|--------|--------------|-------------------------|---|---------------|----------------------|-------|
|  |                      | Male   | Female       | 1                       | 2 | >2            | <12 m                | >12 m |
| Oral condition                                 | Excellent            | 5      | 2            | 2                       | 2 | 3             | 6                    | 1     |
|  | Good                 | 10     | 6            | 2                       | 5 | 9             | 11                   | 5     |
|  | Fair                 | 5      | 7            | 1                       | 2 | 9             | 4                    | 8     |
|  | Poor                 | 1      | 1            | 1                       | 1 | 0             | 0                    | 2     |
|  | I don't know         | 1      | 2            | 1                       | 1 | 1             | 0                    | 3     |
| <i>p</i> -value                                | <b>0.678</b>         |        | <b>0.456</b> |                         |   | <b>0.012*</b> |                      |       |
| Dental visit in the last 12 months             | Yes                  | 15     | 13           | 4                       | 8 | 16            | 8                    | 20    |
|  | No                   | 7      | 5            | 3                       | 3 | 6             | 9                    | 3     |
| <i>p</i> -value                                | <b>0.781</b>         |        | <b>0.802</b> |                         |   | <b>0.013*</b> |                      |       |
| Receiving dental care needed                   | Yes                  | 15     | 12           | 3                       | 8 | 16            | 11                   | 16    |
|  | No                   | 6      | 3            | 2                       | 2 | 5             | 5                    | 4     |
|  | I don't know         | 1      | 3            | 2                       | 1 | 1             | 2                    | 2     |
| <i>p</i> -value                                | <b>0.424</b>         |        | <b>0.386</b> |                         |   | <b>0.706</b>  |                      |       |
| Satisfaction with dental care                  | Very satisfied       | 12     | 7            | 3                       | 5 | 11            | 10                   | 9     |
|  | Somewhat satisfied   | 7      | 5            | 3                       | 4 | 5             | 6                    | 6     |
|  | Somewhat unsatisfied | 2      | 5            | 1                       | 1 | 5             | 4                    | 3     |
|  | Unsatisfied          | 1      | 1            | 0                       | 1 | 1             | 2                    | 0     |
| <i>p</i> -value                                | <b>0.464</b>         |        | <b>0.902</b> |                         |   | <b>0.731</b>  |                      |       |
| <b>* statistically significant (p&lt;0.05)</b> |                      |        |              |                         |   |               |                      |       |



## **3.2 Part 2 – Dental Providers**

### **3.2.1 Descriptive Analyses**

A total of eleven dentists were contacted either by telephone or email and asked to participate in the study. After four months of recruitment, eight dentists agreed to take part. The mean of the variable ‘years since graduation’ from dental school (and including any specialty training program as applicable) for all participating dentists was 17 years (range 11-28 years). Six out of eight participating dentists received specialty training (including Advanced General Dentistry -AGD, General Practice Residency -GPR or hospital training) following dental school. All participating dentists practiced dentistry in cities within the Lower Mainland (Vancouver, North Vancouver, Abbotsford, Port Moody, Burnaby, Surrey), with the exception of one dentist who practiced in Prince George.

On average, the dentists rated their dental training between “Good” and “Excellent” in terms of how well it prepared them to treat individuals with special needs. The average percentage of their practice time spent treating patients with SHCN was 12.1% (range 6%-20%). The dentists treated patients with a wide variety of special health care concerns, but the most common types reported were individuals with autism, bleeding disorders, behavioral disorders, deafness/hearing loss, visual impairments and organ transplant recipients.

Dentists were also asked in an open-ended question format to describe the following: factors that guide their decision to treat individuals with special needs; the difficulties that those patients face getting their dental treatment done; and their recommendations to improve the access of young adults with special needs to community-based dental care, particularly those that are transitioning from regular care at BC Children’s Hospital.

### **Factors that affect the dentists' decisions to treat individuals with special needs:**

The participating dentists reported a number of factors that influenced their decision to treat special needs patients. These factors were categorized into the following general themes:

1. Professional ability or obligation: as one dentist stated "*I don't limit any age of a special needs patient...my limitation is my ability to serve my patient and their family*"., Another dentist wrote: "*As a hospital dentist it is part of my mandate to treat such patients...since we are a tertiary referral centre for these special needs patients we are obliged to treat all of them regardless of the severity of the disease process*". Both statements imply that providing the care to individuals with special needs is one of their professional obligations.
2. [Dentist's] established reputation in the community: one dentist stated in his response: "*They know they will be seen*".
3. Patient cooperation/behavior: this factor was stated repeatedly by most of the participating dentists. One dentist commented: "*ability to cooperate for an exam...patient's safety of exam and treatment*".
4. Parent/caregiver issues: one dentist stated that "*parent motivation and expectation*" is a factor to consider when making a decision to treat individuals with special needs. Another practitioner reported that the patient's financial situation was also a factor that influenced their decision to treat patients with special needs.

### **Difficulties that individuals with special needs face getting their dental treatment done:**

The difficulties from this question were also categorized into themes in order to best represent the answers provided by the participating dentists. The identified themes are as follows:

1. Access to GA: this difficulty was the response that the dentists repeated most often. In addressing it, they identified the following primary issues: *“GA access”, “lack of OR time”, “locating a facility willing to undertake care..”, “understand ideal treatment not possible, except under GA”, “comorbidities which limit extensive work to be done in hospital setting with OR time...”* and *“there is a lack of hospital time to treat these patients”*.
2. Finances: one dentist mentioned: *“family may not be able to afford the treatment cost”* and *“financial burden on the family as dentistry is expensive”*.
3. Insurance coverage: as stated by one dentist: *“insurance doesn’t take into account the extra time these patients require to treat or to coordinate care”*. Another dentist also stated: *“the reimbursement levels are very poor...many times we are losing money on treating these patients”*. One dentist provided an example of some insurance coverage deficiency and stated: *“Whereas BCDP covers most of their treatment, some options like crowns etc are not covered and provide less flexibility when assessing options”*.
4. Behavior impedes treatment: as one dentist stated *“sometimes the patient behavior is the major difficulty”*. Another dentist wrote: *“many of these patients are difficult to treat”*.
5. Caregiver reluctance: parents or caregiver may contribute to the difficulty in accessing dental care. Parents *“denial”, “hesitation”, “logistics”* were reported by a number of dentists.

**Dentists' recommendation to improve the access of young adults with special needs to community-based dental care, particularly those that are transitioned from regular care at BC Children's Hospital:**

The recommendation from dentists were also categorized under this question into five themes, as follows:

1. BCCH issues: as stated by many dentists: *"BCCH needs to provide us with updated and accurate treatment records ..."*, *"BCCH needs to streamline the process of transition"*, *"provide an early transition"*.
2. Hospital access: as stated by one dentist: *"I think that more hospital time needs to be available for special needs and medically compromised patients"*.
3. Funding/financial: this recommendation also stated repeatedly by many dentists: *"government funding needs to be maintained"*, *"government coverage"*, *"reimbursement levels need to be better so that the dentist can see these patients without losing money. I think that would make more dentists want to treat these difficult cases."*
4. Multidisciplinary community-based clinic(s) providing GA/deep sedation to allow access to specialty dental care services as one dentist stated: *"multidisciplinary clinic at hospital with GA/sedation access..."*.
5. Education: education of both dentists and YASHCN caregivers, as two dentists stated: *"yes improvements need to be made, the process, the education of dentists to care for these individuals"*, *"patient education and support"*.

In summary, although the dental providers suggest that BCCH could improve its transition process, the main thrust of their concern was related to limited funding, available and

appropriately trained providers and access to suitable facilities that could support the care for patients once they “graduated” from BCCH.

## Chapter 4: Discussion

This research explored the transition experience of young adults with special health care needs (YASHCN) who had been discharged from dental care at BCCH-DD. Previous research related to access to care involved the “active” population of CSHCN at BCCH-DD or evaluated other aspects affecting the population of individuals with special needs. Therefore this research on the transition to adult care seemed a logical “fit” within this theme to further expand on the issues (20,46,47). Importantly, the present study was the first to attempt to evaluate how BC families with YASCHN managed their transition from pediatric to adult dental services, seeking the perspective from both sides of the access “equation”: the families or youth themselves and the community dental providers who care for them. Our objective was to determine if young adults with special health care needs who transitioned from care at BCCH-DD were successful in establishing a dental home and satisfied with the care from that new dental home. Furthermore, we sought to gain a deeper understanding of any challenges in this transition process and beyond from the perspective of dentists who care for YASHCN.

Our results from the YASHCN 5-question “quick” survey revealed that 70% of our sample had seen a dentist, at least once, in the last 12 months. By contrast, during their time as an “active” patient, BCCH-DD would have been proactive in monitoring these patients closely with twice yearly recall visits and follow through to provide prompt dental care because of their high risk of oral disease and challenges with home care. Therefore, our finding may indicate a delay in access to dental services and suggests that there may have been issues with the transition process. Although there has been no previous study in BC that evaluated the access to adult dental care for our sample population, our results are comparable to an Ontario study’s finding

that 73.2% of YASHCN were able to access dental services. A very recent report by the Canadian Dental Association found that 75% of all Canadians visit a dental clinic annually and 86% do so at least once every 2 years (51). This suggests that our sample has equivalency of access to dental care services when compared to the national average, although with obvious potential for improvement.

More than half (57%) of our participants subjectively reported having “good” or “excellent” oral health status. Other studies also found that the majority of developmentally disabled individuals surveyed tend to report “good” or “fair” oral health status (52–54). The different rating scales used by different studies may possibly explain this inconsistency in self-reported oral health status. Moreover, in contrast to the above-mentioned studies which were conducted mainly on the developmentally disabled population, responses in our study were collected from YASHCN that had a variety of special health care issues including medical co-morbidity, which could offer another explanation for the inconsistency. One would expect intellectual or developmental disability to be more likely to challenge the dentists’ ability to adequately manage dental care in a community-based dental office setting than a less complex medical co-morbidity. It should be noted that the figure indicated by our participants’ subjective responses was much lower than the national average stated by the Canadian Dental Association, which found that 84% of Canadians report their oral health as good or excellent. Although our study shows that YASHCN has a slightly comparable level of access to dental care when compared to the national average of Non-YASHCN, the self-reported oral health status was vastly lower than the reported national averages (57% and 84% respectively)(51). The large difference in reporting the oral health status maybe explained by the fact that the responses in our study were given largely by the caregivers for the YASHCN, who typically tend to be inaccurate

judges of the actual oral health status of their charges, as evidenced by a study of 103 special needs patients with an average age of 17 years old. In this study, the majority of caregivers (99%) and dentists (76%) seemed to have underestimated the actual dental treatment needs of the special needs patients when compared to the clinical estimation (55).

Our results show that about two-thirds of the caregivers felt that YASHCN have received the necessary dental care. Moreover, 8 of 10 responded that they were “very satisfied” or “somewhat satisfied” with their current access to dental care. Our result is consistent with past research which found that caregivers of developmentally disabled individuals also reported that they were very satisfied with the institution’s dental care services and perceived these services to be better than its medical services (~70%) (56). To our knowledge, no study has evaluated YASHCN’s satisfaction level regarding access to dental care in BC. Therefore, the present study may provide a baseline for comparison when future studies are conducted in the same area.

Despite the fact that the majority (70%) of YASHCN had seen a dentist in the past one year, this study supports previous literature which found that some of these individuals with special needs continue to face barriers when accessing dental services. For those unable to access dental care, these barriers include the complexity of YASHCN’s medical conditions and caregivers’ lack of awareness about the importance of YASHCN’s dental needs. Our sample participants also reported some additional issues related to the transition process, in particular from those transitioned to VGH-DD, including poor communication from staff and the long waiting time to receive care. However, it is important to note that the present study was conducted during a period when VGH-DD was undergoing significant disruption at the administrative level, which may have reflected negatively in some responses from YASHCN and/or their caregivers. Other barriers that were reported by previous investigators, such as



transportation, were not mentioned by our subjects. This omission may be attributable to the well-connected public transportation system in Vancouver and the fact that the majority of our subjects live in communities within the Lower Mainland. Alternatively, it could also indicate that Metro Vancouver residents are quite accustomed to transportation barriers as part of their everyday life in a sprawling metropolitan centre, and did not consider it extraordinary. Also, our sample was relatively small and the majority reported being satisfied with their access to dental care in BC. A larger sample might have revealed a greater range of satisfaction levels.

It was interesting to note that the BCDA website listed 146 general practice dentists and dental specialists in Metro Vancouver as accepting new patients in the category specific to children/youth with special health care needs, or PWD (Persons with Disabilities). However, when contacted, a number of those admitted that they actually did not care for PWD. This discovery suggested that the information provided on the BCDA website was incorrect, out-of-date or at least somewhat misleading. Of those 11 dentists ultimately identified as “actual” dental providers for PWD, the response rate of 8 out of 11, or 72% was favourable. The majority of the participating dentists (6 out of 8) had received additional specialized training that they felt was helpful in preparing them to treat individuals with special health care needs. These results are consistent with other studies confirming that additional education beyond undergraduate degree training programs increases the likelihood of dentists treating special needs patients (57–60). Of note, these dental providers indicated their average patient load of PWD was 12.1%, with a reported maximum of 20%.

Only one of the dentist-respondents practiced outside the Lower Mainland or Metro Vancouver area. The uneven geographic distribution of dentists in the sample may be attributed both to the disproportionate distribution of both dentists and population in our vast province.

Also, this may be attributed to the sample selection process, as dentists were chosen based on professional connections that identified them as being known to see and treat YASHCN in the Lower Mainland. As mentioned, the multiple contacts we made during the dentist recruitment process revealed that many dentists whom the BCDA website listed as accepting “Medically Challenged Patients” did not, in fact, do so. This disparity may be attributed to the fact that most special needs patients require treatment and sometimes even their routine maintenance examinations under general anesthesia. Such a service is only available to those privileged at publicly-funded hospitals (e.g. VGH, BCCH). Alternatively, a few pediatric dental offices are able to coordinate access with community-based private surgical facilities that provide general anesthesia.

The dentists who participated in the present study have identified multiple factors that influence their decision to treat individuals with special needs, including: acceptance of perceived professional ability or obligation, maintenance of reputation, patient’s ability to cooperate and evidence of caregiver or parent motivation. Previous reports indicate that both professional ability and patient cooperation are important factors that influence a dentist’s decision to treat SHCN individuals (58,61). However, to our knowledge, dentists’ reputation in the community and caregiver motivation have not been previously suggested as motivating factors to treat YASHCN. It may be possible that in communities where YASHCN’s access to dental care is limited, parents may network or tend to seek the opinion of other parents (of special needs individuals). As was evidenced in a previous study, this may be their best option for finding a dentist capable and willing to treat their YASHCN (20).

Additionally, our dental providers reported various difficulties that impair their ability to provide treatment for their special needs patients. These difficulties include limitations of access

to general anesthesia, patient financial limitations, limited insurance coverage, patient's behavior and caregiver reluctance. Previous studies have emphasized similar barriers (16,62–66). Of these reported difficulties, our study did not find “low family income” and a “shortage of adequately trained dental providers” as barriers. It is worth mentioning that we were not able to collect any family-related variables, such as income and the availability of insurance coverage because too few subjects were agreeable to participate in the longer survey that would have collected that information. Due to this limitation, our study was unable to assess the impact of these family-level factors on YASHCN's access to dental care.

The participating dentists provided some helpful recommendations to improve the access of young adults with special needs to community-based dental care. Two of these factors, suggesting that improving funding/financial support would be needed and improved education for both dentists and parents, are reported consistently in the literature (58,67–70). In general, YASHCN usually present with more dental needs than non-YASHCN as a result of their medical condition. Therefore, in many cases, the amount of coverage provided by MSDSI may not be adequate to cover the dental needs of YASHCN. Moreover, the fee remuneration provided through this coverage is significantly lower than that listed by the fee guide of the British Columbia Dental Association. The disparity in reimbursement for individuals who require more time to treat may also have discouraged more dentists, making them unwilling to see and treat YASHCN.

Previous studies found that lack of undergraduate education and clinical exposure to the dental management of PWD are two main factors contributing to dental providers being uncomfortable with treating special needs patients (21,71). Dental students who experienced treating PWD rated being more comfortable to provide future care to PWD after having the

experience during their training program (31). In our study, most participating dentists received additional training and education after dental school and they rated their education as “good” or “excellent” in preparing them to manage special needs patients.

The limited available literature that assessed YASHCN parental attitudes toward oral health showed mixed results (72–74). However, in addition to providing dental care, BCCH dental providers fully engage the caregivers during the time their CHSCN is an active patient to educate and instill the importance of dental care during their many maintenance visits. Once discharged from BCCH-DD, caregivers are again reminded of the importance of maintaining optimal oral hygiene of their YASCHN charges, and they are also informed when to schedule the next dental recall with the next dental care provider. However, without this continual reinforcement, some busy caregivers may let maintenance care lapse.

The other two recommendations were related mainly to the health care system in BC. One dental provider suggested that the transition process for YASHCN could be improved, but did not provide exact details about how this could be accomplished. The process of transition from BCCH-DD has improved more recently with the changes made in VGH-DD. Also, the trend in healthcare today for more ‘patient-centered care’ suggests that there will be continued efforts to drive improvements in the area of transition.

Another dentist suggested the establishment of multidisciplinary clinic that enables GA/deep sedation under the care of specialists. In reality, including anesthesia support experienced in the management of adults with special needs would be an essential point of consideration. Such a facility also requires the collaboration of different dental specialists for the design and implementation of customized and comprehensive treatment plans for PWD that address all the requirements of dentistry. Examples of this would be a dental clinic that enables

the coordination of care with prosthodontic, endodontic, periodontal and oral maxillofacial surgeons. A sustainable, multidisciplinary clinic specifically structured to serve PWD could be a favourable solution to their dental access issues. However, the few current number of dentists who are able to provide such sustainable care and the ability to garner provincial or private funding to establish such a clinic may be two major obstacles to achieving this solution.

#### **4.1 Limitations of this study**

First, as the present study is cross-sectional, our findings cannot establish any causality. Moreover, as the “access to care” issue is heavily linked to the type of healthcare system where the YASHCN live, and since healthcare systems are unlike between countries and even within provinces in the same country, one should be cautious when generalizing results to YASHCN in other provinces or countries.

Second, the initial study design had to be modified during the research process. This was mainly due to the very low numbers of YASHCN who agreed to participate in the second, more detailed part of the study. The initial plan was to gather more information from YASHCN and their caregivers by inviting them to BCCH-DD. The added value of this part of the study was to enable a brief clinical exam of YASHCN. This information would provide the comparison of the actual oral health status to the self-reported status. Also, this opportunity would permit the collection of more detailed survey information to include items such as family income and parental education. However, only two YASHCN agreed to complete these parts of the study after the quick survey had been completed. Given the small number, it was decided to focus efforts on recruitment for the quick survey. Thus, only the most basic information was gathered about the access, availability and satisfaction of YASHCN and their caregivers with regard to

dental care.

Third, the responses in this research were largely by proxy, given that the majority of surveys were completed by caregivers of YASHCN (90%). For example, caregivers were asked to answer a question about their YASHCN's oral health status. It is conceivable that caregivers may have under-reported their YASHCN's oral health status based on their own understanding and awareness of oral health. In fact, as mentioned earlier in the discussion, parents tend to underestimate their YASHCN dental needs.

Lastly, the study population consisted of YASCHN who were former "active" BCCH-DD patients with birthdates up to and including 1996, and had been discharged from BCCH-DD prior to January 1<sup>st</sup>, 2015. It is important to note that subjects were selected only if their actual dental records were physically available on-site in the BCCH-DD archived file storage. Usually, discontinued dental charts are archived off-site after 3 years and it is very costly to retrieve them. Therefore, this study provides only short-term follow-up, with the maximum post-discharge time of 24 months from BCCH-DD. Consequently, our results may not reflect the actual ease or difficulty of access to dental care for those YASHCN who had been out in the community for a longer period of time. Moreover, the high level of "excellent/good" oral health status reported may have been skewed by the fact that oral health problems had not had the time to develop after years of regular dental supervision at BCCH-DD.

## **4.2 Future directions**

One purpose of this study was to assess if young adults with special health care needs who transitioned from care at BCCH-DD were successful and satisfied in establishing a new dental home. Furthermore, the study aimed to gain a deeper understanding of any challenges to

this transition process from the perspectives of dentists who care for YASHCN. It would have been desirable to have more participants complete the detailed survey to explore the effects of family income and parental education on the access equation. The initial design structure involved having the YASHCN complete a short survey initially, and then seek consent to complete a more detailed survey. The detailed survey aimed to collect as much information as possible, especially on the demographic level, to better understand additional enabling factors or barriers to YASHCN's access to dental care (e.g. income, parental education). However, due to the low number of subjects who agreed to participate in the detailed survey, it was decided to focus on the first quick survey, which asked basic questions about their access to dental care services. Although the information gleaned from the basic quick survey was of value as "basic exploratory" information, future studies in this field will need more robust recruitment measures to ensure that additional information is collected about YASHCN. This may present challenges for a population that may be somewhat "over-sampled" for these types of surveys while under care at BCCH. Nevertheless, this will help us to probe for more in-depth understanding of all the personal-level (e.g. income) and system-level (e.g. insurance coverage) factors that may impact their access level to dental care.

In addition to the inclusion criteria of the study, subjects were selected only if their actual physical charts were still available in the BCCH-DD archive. Usually, inactivated dental charts are archived off-site and it is financially challenging to retrieve them. This limited our participant sample pool to those who were dismissed in the recent past. With provision for the extra cost, future studies could be undertaken to retrieve the charts of older patients who have been out in the community for a longer period, to permit follow-up to assess their status longer-term, better gauge the sustainability of their dental home and offer reflection regarding their overall transition

experience. In order to facilitate this type of longer-term follow-up, perhaps some consideration could be given to securing consent from the YASHCN/caregiver for future contact for the possibility of follow-up as part of the transition process at the time of discharge from BCCH.

The present study provides the first step toward a better understanding of YASHCN access to dental care following discharge from pediatric dental care services at BCCH-DD. In addition to the above-mentioned future research directions, this study supports the following practical recommendations for the dental community, policy makers and dental training programs:

1. Although there has recently been a great deal of positive change in the referral process between BCCH-DD and future dental care providers for YASHCN (VGH, community-based dental providers), this process could be further enhanced (e.g. creation of a new electronic comprehensive referral form). The transition process could possibly be better co-ordinated and timed with that of other BCCH services as much as possible. Therefore, it is recommended that BCCH-DD refine its process to enhance current transition procedures:
  - a. A list of dental providers that accept YASHCN should be expanded. This can be offered to families when the transition plan is initiated around 15 to 16 years of age, prior to discharging from care. Where possible, YASHCN will be placed with the family dentist to facilitate some continuity, given there is familiarity and awareness of acceptable process where other family members attend.
  - b. All attempts should be made to ensure that patients referred to VGH-DD are appropriate for that institution i.e., complex co-morbidity or severe intellectual



disability definitely in need of hospital-based general anesthesia access and support for their on-going dental care. This will ease the burden on the existing publicly-funded hospital clinics by not overwhelming VGH-DD with inappropriate cases that could possibly be managed in the community.

- c. BCCH-DD may further assist families by liaising with their other hospital services & medical providers to ensure the timing of transition is appropriate.
- d. BCCH-DD would prepare a detailed letter of introduction to the new dental provider, fully outlining the past dental history and current medical status. This could be prepared once the decision to transition has been made. Caregivers would sign a consent for release of this information at their final visit.

2. Dental Benefit Funding/financial support for families with YASHCN and PWD:

This research supports the need for better funding/financial support for their dental care which may be accomplished through advocacy with MSDSI to improve dental benefits coverage for families supporting YASHCN. This may include an increase in the annual financial coverage of dental benefits for PWD, and possibly a modification of dentists' reimbursement rate that at least better approximates the BCDA suggested dental fee guide, given the added time and responsibility innate to caring for these patients.

3. The BCDA website has an excellent search engine for families to identify dentists who accept PWD. However, multiple attempts made to recruit dentists using this listing demonstrated clearly that the list is not accurate. Therefore, the BCDA should review and confirm that their network of dentists listed as willing and able to treat PWD is a true representation.

4. Advocacy to establish a community-based multidisciplinary dental clinic/outpatient surgical or sedation facility that is able to provide necessary care under GA/deep sedation for those patients that may have less profound or have mildly compromised medical disability. Careful case selection would have to be undertaken to ensure patients can have their care managed without undue medical risk in an out-patient facility. Diverting some of these patients from tertiary-care hospital settings is key to keeping wait times for dental care manageable.
5. Enhance dental professional curricula to further incorporate focused education and provide clinical exposure to special needs individuals, particularly in the autism spectrum. This will have its limitations of course because dental curriculum is quite compressed already, and not all dental students have the disposition nor the desire to manage these patients. It may be more prudent to focus efforts to those interested, through the development of externship opportunities, or even providing an elective for the final year of the undergraduate dentistry program. An example of this type of experience may present in the newly established Pacific Autism Centre in Richmond, BC which aims to partner with UBC Dentistry to provide service-learning opportunities for dental hygienists, dental specialty trainees and other health care professionals.
6. UBC Dentistry in collaboration with Vancouver Coastal Health could refine the existing GPR program to establish an accredited specialty residency program or fellowship with specific emphasis on the dental needs of PWD in both ambulatory and OR settings. Focused programming would fully entrench skills of behavior modification needed to manage those with intellectual disabilities, alongside in-depth understanding and integration of medical management that this population often needs. This type of training

would expose the “generalist” dental provider to both community and hospital-based components and overall greatly improve the comfort level needed to enable focused care for PWD. Upon completion, graduates would be able to justify petitioning for a fee differential and perhaps could be given higher priority for privileges at community hospitals beyond Metro Vancouver, based on the community’s specific needs. Having a specialty designation would also lend itself to a position of strong advocacy to government stakeholders and policy-makers. Based on the reflections from the dental providers in this study there may be interest, especially those wishing to practice outside Metro Vancouver.

### **4.3 Conclusions**

To our knowledge, this is the first study to explore the dental care transition experience of YASHCN in BC from both sides of the equation: YASHCN, their caregivers and their dental providers. At least in the short-term, the majority of YASHCN/caregivers were able to sufficiently access dental care and expressed satisfaction with their present dental status and access to dental care access. However, YASHCN/caregivers did confirm previously identified barriers to accessing dental care, which included: the complexity of YASCH’s medical needs, a lack of awareness regarding YASHCN’s dental needs, and issues related to the transition process. Dental providers confirmed that YASHCN reported difficulties accessing dental care. They made several recommendations that they felt would improve both the transition process and the dental access of YASHCN including personal (behavioral, age-related), family (caregiver involvement) and system-related (insurance, hospital/anesthesia access) issues. These recommendations, as well as the concerns expressed by YASHCN and their caregivers should be

taken into account in the refinement of the transition experience from BCCH-DD to adult care settings.

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# Appendices

## Appendix A - Dentist

### A.1 Letter of invitation



UBC DENTISTRY



#### Letter of Invitation

Dear Dr. \_\_\_\_\_

I would like to announce that Dr. Mazin Algahtani, one of our Pediatric Dentistry Graduate Students from UBC is now conducting a research study in our Dental Department at BC Children Hospital (BCCH-DD). The study entitled *“Dental care beyond BC Children’s Hospital: The transition experience for young adults with special health care needs”*. His research supervisor is Dr. Karen Campbell, Clinical Associate Professor in Pediatric Dentistry at UBC and Chief of Dentistry at BC Children’s Hospital.

The purpose of Dr. Algahtani’s study is to determine if young adults with special health care needs (YASHCN) transitioned from care at BCCH-DD were successful and satisfied in establishing a sustainable dental home. We also wish to better understand any challenges or enabling factors in their transition process and hear YOUR perspective as a dental provider who cares for YASHCN.

We understand that many families/individuals with special needs are facing difficulties receiving needed dental care and solutions need to be found. We want to be reassured that these families are taken care of when they are discharged from our care. You can help us explore this issue by providing information about your own dental care experiences in dealing with these individuals, the barriers that you think they face, and to hear your thoughts and recommendations to improve their access to dental care.

You will be invited to participate in a 20-30 minute in-person interview to share the rich background of what you do in your practice in terms of treating individuals with special needs. Before you decide whether or not you would like to participate, it is important for you to understand in detail why we are doing this research and what it would involve for you if you decide to participate. Please take time to read the enclosed consent carefully and take time to think about whether or not you would like to take part. Within 2 weeks, we will contact your office to question about your decision of participating in this study.

We believe that the results of this study will broaden our understanding of the current accessibility and satisfaction levels, and barriers to dental care services among YASHCN living in the Lower Mainland. From there, collaboration between the families of YASHCN, dental care providers, and the local dental and special needs associations can be expanded in an effort to improve dental care for YASHCN. If you have further questions about the study, please feel free to contact the study team below.

Kind regards,  
Dr. Karen Campbell

## A.2 Consent



UBC DENTISTRY



Consent Form for Dental Providers **Title of Research Project:** *“Dental care beyond BC Children’s Hospital: The transition experience for young adults with special health care needs”*

Who is conducting the study?

**Principal Investigator:**

Dr. Karen Campbell  
Chief of Dentistry, BC Children’s Hospital &  
Clinical Associate Professor, UBC

**Co-Investigator:**

Dr. Mazin Algahtani  
Graduate Student in Pediatric Dentistry, UBC  
\* This research is part of Mazin Algahtani’s graduate  
MSc thesis

Why should you take part in this study?

As a dentist who treats young adult with special health care needs (YASHCN), we would like to hear from you about your experience in treating these individuals, the issues surrounding their access to dental care and to obtain your recommendations in how to improve their access and utilization of dental care.

*Your participation is entirely voluntary:* It is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what this research study involves. This consent form will tell you about the study, why the research is being done, what will happen during the study and the possible benefits and risks.

If you wish to participate, you will be asked to sign this form. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reasons for your decision.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate. You do not waive any of their legal rights by signing this consent form.

**Please take time to read the following information carefully before you decide.**

Background to the study:

We often hear from caregivers that they have difficulty getting dental care for their young adult with special needs, but no one has ever collected information about it. We also want to talk to the dentists that do provide care for adults with special needs, hear their challenges in doing so and why they think many dentists choose not to.

What is the purpose of the study?

To gain a better understanding of: 1) how long the transition process from BCCH-DD to a new “adult” dentist took, (or if at all); 2) factors that helped/challenged the process; 3) if dental health was maintained or if it got worse while this transition occurred; 4) how satisfied the YASHCN or his/her caregiver are with the new “adult” dentist; 6) and from the “adult” dentist, to hear what helps them or makes it difficult for them to provide care for adults with special health care needs. Once we examine this information we can begin the work to make the ‘transition’ for young adults from BCCH-DD to an adult dentist an easier and more consistent experience.

Who can participate in the study?

You may choose to participate if you are:

- Dentist who treats young adult with special health care needs (based on the information obtained from the College of Dental Surgeons in British Columbia (CDSBC) and the British Columbia Dental Association (BCDA) websites).

What does the study involve?

**Your office will receive a phone call from the co-investigator within 2 weeks asking about your decision of participating in this study.** If you agree to participate, there will be an arranged 20-30 minutes in-person interview. We would like to learn about your dental education background, experience with treating YASHCN and to have your recommendations in how to improve their access and utilization of dental care services.

Study Results:

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books.

Is there any way being in this study could be bad for you?

We may ask you to share some personal information (eg., your dental education background). Should you feel uncomfortable about these questions, you have the right to skip over answering these questions or refuse further participation. The investigator will audiotape and transcribe your response on some of the survey's questions. Participation in the study will require about 20-30 minutes of your time, which rarely may extend beyond this allocated time.

What are the benefits of participating?

You may or may not directly benefit from participating in the study. As a thank-you for participating we will provide a \$10 Starbucks coffee card.

What happens if I decide to withdraw from the study?

You do not have to provide any reasons for your decision to withdraw from the study. We will retain any data collected up to the point of your withdrawal from the study.

How will your privacy be maintained?

Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent to the disclosure. All audiotape recordings will be stored on a password protected computer and external network for two years from the date of collection, then, they will be all destroyed. All documents will have a code number, not a name, and will be stored in a locked filing cabinet. During the study period, only the principal investigator and the co-investigator will have access to the research materials. However, research records and dental records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC Research Ethics Board for the purpose of monitoring the research. However, no records which identify you by name or initials will be allowed to leave the Investigators' offices.

Who do I contact if I have questions about the study during my participation?

The persons who may be contacted about the research, the Principal Investigator and Co-Investigator, are listed at the top of page 1 of this form.

Who do I contact if I have questions or concerns about my rights as a subject during the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the

University of British Columbia Office of Research Ethics by e-mail at RSIL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

**Title of Research Project:** *“Dental care beyond BC Children’s Hospital: perspectives on the transition experience for young adults with special health care needs”*

Dentist Consent to participate:

I acknowledge that the purpose of this study has been explained to me and that any questions that I have asked have been answered to my satisfaction.

- I have been informed that I have the right not to participate and the right to withdraw. I also understand the benefits (if any) of participating in this survey.
- I know that I may ask now, or in the future, any questions I have about the study or the research procedures.
- I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law.
- I also understand that I do not waive any of my legal rights by signing this consent form.
- I am aware that I will receive a signed and dated copy of this consent form.

I \_\_\_\_\_ (Dentist PRINTED NAME) hereby consent to participate as a subject in this study.

I wish to be informed about the results of the study      YES    NO    (please circle)

I give my permission for the study team to contact me in future should clarification of any information be necessary                      YES    NO    (please circle)

Signature of dentist: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Investigator/Designate (PRINTED): \_\_\_\_\_

Signature of Investigator/Designate: \_\_\_\_\_

### A.3 Survey

Dental care after BCCH

Dentist Survey

Subject ID: \_\_\_\_\_

#### Questions 1 to 9 ask information about dentists who treats YASHCN

1. **What year did you graduate from dental school?**
  - Year.....
  
2. **Did you have any specialty training (including AGD, GPR or hospital training) after dental school:**
  - No
  - Yes (please specify institution) ..... Year.....
  
3. **How would rate your dental training in terms of preparing you to treat individuals with special needs?**

Poor                      Fair                      Good                      Excellent

I-----I-----I-----I
  
4. **Where is your practice located?**

City .....Postal code
  
5. **What percentage of your patient load is spent treating patients with SHCN?**

\_\_\_\_\_
  
6. **Please indicate the types of special health care need that you most commonly see in your practice: (Check all that apply)**
  - Autism spectrum disorders (ASDs)
  - Bleeding disorders (vonWillebrand, hemophilia, ITP)
  - Behavioural Disorders (Attention Deficit/Hyperactivity Disorder (AD/HD)
  - Pervasive Developmental Disorder
  - Cerebral Palsy
  - Deafness/Hearing Loss, Visual impairments
  - Down Syndrome
  - Psychiatric Disorder/Emotional Disturbance
  - Neurological disorders (Epilepsy, Traumatic Brain Injury
  - Severe cognitive delay, reading/learning disabilities
  - Speech and Language Impairments
  - Spina Bifida
  - Craniofacial anomalies
  - Neuromuscular disorders (Duchenne’s muscular dystrophy, ataxia)
  - Organ transplant patients (renal, liver, cardiac/lung)
  - Other (please specify) .....
  - Don’t know

7. **Tell us about the factors that affect your decision to treat individuals with special needs? (type and severity of the condition, patient’s age.. etc)**

.....

.....

.....

8. **From your experience, what are the difficulties that those patients face to get their dental treatment done? Examples: (*Person-level*: behavior, type and severity of his/her condition. *Family-level*: family structure, financial issues, transportation. *System-level*: insurance coverage, shortage of dentists who accept them, transition issues).**

.....

.....

.....

9. **From your experience, what would you recommend to improve the access of young adults with special needs to community-based dental care, particularly those that are transitioned from regular care at BC Children’s Hospital?**

.....

.....

.....



## Appendix B - YASHCN/caregiver

### B.1 Letter of invitation



UBC DENTISTRY



**Title of Research Project:** *“Dental care beyond BC Children’s Hospital: The transition experience for young adults with special health care needs”*

**Principal Investigator:** Dr. Karen Campbell  
Chief of Dentistry, BC Children’s Hospital &  
Clinical Associate Professor, UBC

**Co-Investigator:** Dr. Mazin Algahtani  
Graduate Student in Pediatric Dentistry, UBC  
\* This research is part of Mazin Algahtani’s graduate  
MSc thesis

**We invite you to participate** in a research project entitled *“Dental care beyond BC Children’s Hospital: The transition experience for young adults with special health care needs”* because you/your son/daughter were former dental patients here.

The purpose of our research project is to better understand the dental care experience of you/your son/your daughter after leaving Dentistry Department at BC Children’s Hospital (DD-BCCH). Should you choose to participate, you will be asked to answer a short phone survey which will probably take 5 minutes of your time. Then, you will be provided the option of coming to DD-BCCH for one visit to receive a brief dental check-up and answer a more detailed survey which will in-total take about 45 minutes.

You may or may not directly benefit from participating in the study. As a thank-you for participating we will provide a small package of oral health supplies and reimbursement for public transit/parking up to a \$15.00 maximum (upon presentation of receipt) if you decide to participate in the dental visit at DD-BCCH.

Before you decide whether or not you would like to participate, it is important for you to understand why we are doing this study and what it would involve for you/your son/your daughter if you decide to participate. Please take time to read the enclosed letter of information/consent sheet carefully and take time to think about whether or not you would like to take part.

If you have any questions, please feel free to contact us (see above for contact information).

Thank you for your consideration,

Yours sincerely,

Dr. Karen Campbell

Chief of Dentistry, BC Children’s Hospital &  
Clinical Associate Professor, UBC

## B.2 YASHCN assent form



UBC DENTISTRY | UBC THE UNIVERSITY OF BRITISH COLUMBIA



### Young Adult with a Special Need - Assent Form

**Study Title:** *Dental care after BC Children Hospital*

I am being invited to be part of a research study. A research study tries to find if young adults like me can see a dentist and receive dental care. It is up to me if I want to be in this study. No one will make me be part of the study. Even if I agree now to be part of the study, I can change my mind later. No one will be upset with me if I choose not to be part of this study.

#### **Why Are We Doing This Study?**

This study is trying to find out if young adults like me (with special health care needs) are able to get dental care like the care we received from BC Children Hospital. Researchers need to understand our dental needs and help let others know about our needs. I am being invited to be a part of this study because I have a special health need and I had my dental care before at BC Children Hospital.

#### **What Will Happen in This Study?**

If I agree to be in this study, I will go to see the dentist for 45 minutes (1 visit). They will do a quick dental checkup and my parents will answer a few questions on my behalf.

#### **Who Is Doing This Study?**

**Dr. Karen Campbell** and other dentists from Children's Hospital will be doing this study. They will answer any questions I have about the study. I can also call them at:

\_\_\_\_\_ **Extension** \_\_\_\_\_ **or** \_\_\_\_\_.

#### **Can Anything Bad Happen to Me?**

Nothing in this study will cause anything bad to happen to me.

#### **Who Will Know I Am in the Study?**

Only my dentists and people who are involved in the study will know I am in it. When the study is finished, the dentists will write a report about what was learned. This report will not say my name or that I was in the study. My parents and I do not have to tell anyone I am in the study if we don't want to.

#### **When Do I Have To Decide?**

I have as much time as I want to decide to be part of the study. I have also been asked to discuss my decision with my parents.

Now If I put my name at the end of this form, it means that I agree to be in the study.

My name: \_\_\_\_\_

My signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Original form to:**  
Research Team

**Copies to:**  
YASHCN/Parents

## B.3 Consent



UBC DENTISTRY | UBC THE UNIVERSITY OF BRITISH COLUMBIA



### Consent Form for YASHCN/Parents

**Title of Research Project:** *“Dental care beyond BC Children’s Hospital: The transition experience for young adults with special health care needs”*

Who is conducting the study?

**Principal Investigator:**

Dr. Karen Campbell  
Chief of Dentistry, BC Children’s Hospital &  
Clinical Associate Professor, UBC

**Co-Investigator:**

Dr. Mazin Algahtani  
Graduate Student in Pediatric Dentistry, UBC  
\* This research is part of Mazin Algahtani’s graduate  
MSc thesis

Why should you take part in this study?

As a former patient of BC Children’s Hospital Dept. of Dentistry (BCCH-DD) we would like to hear from you about your ‘transition’ experience to arrange dental care for yourself or your son/daughter after being discharged from BCCH-DD due to age. From this study, we hope to learn about the challenges of finding a new dentist and how satisfied you’ve been with the process and present care.

Your participation is entirely voluntary: It is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what this research study involves. This consent form will tell you about the study, why the research is being done, what will happen during the study and the possible benefits and risks.

If you wish to participate, you will be asked to sign this form. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reasons for your decision.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate nor will you lose the benefit of any dental care to which your son/daughter is entitled or is presently receiving. Subjects do not waive any of their legal rights by signing this consent form.

**Please take time to read the following information carefully before you decide.**

Background to the study:

We often hear from caregivers that they have difficulty getting dental care for their young adult with special needs, but no one has ever collected information about it. We also want to talk to the dentists that do provide care for adults with special needs, hear their challenges in doing so and why they think many dentists choose not to.

What is the purpose of the study?

To gain a better understanding of: 1) how long the transition process from BCCH-DD to a new “adult” dentist took, (or if at all); 2) factors that helped/challenged the process; 3) if dental health was maintained or if it got worse while this transition occurred; 4) how satisfied you/your caregiver are with the new “adult” dentist; 6) and from the “adult” dentist, to hear what helps them or makes it difficult for them to provide care for adults with special health care needs. Once we examine this information we can begin the

work to make the ‘transition’ for young adults from BCCH-DD to an adult dentist an easier and more consistent experience.

#### Who can participate in the study?

You may choose to participate if:

- You or your young adult was a former patient at BCCH-DD;
- you are comfortable communicating in English or can bring someone you trust to translate for you

#### What does the study involve?

**You will receive a phone call from the co-investigator in 2 weeks asking about your decision of participating in this study.** If you agree to participate, we will conduct a quick survey over the phone, then if you wish, we can arrange an appointment at BCCH dental clinic to complete a brief inspection of your/your son/daughter’s teeth & oral cavity and interview you/your son/daughter to learn about yourself, your family situation, any medical conditions, and any dental experiences since leaving BCCH. This is a 45 minute appointment. We would also like to review your/your son/daughter’s past dental chart to see what your/his/her dental status was at the time of discharge from BCCH.

#### Study Results:

The results of this study will be reported in a graduate thesis and may also be published in journal articles and books.

#### Is there any way being in this study could be bad for you?

We do not think there is anything in this study that could harm you or be bad for you. We may ask you to share some personal information (eg., range of family income). Should you feel uncomfortable about these questions, you have the right to skip over answering these questions or refuse further participation. The investigator will audiotape and transcribe your response on some of the survey’s questions. Participation in the study will require about 45 minutes of your time, which rarely may extend beyond the time for your son/daughter’s dental visit.

#### What are the benefits of participating?

You may or may not directly benefit from participating in the study. However, if you decide to come to BCCH-DD, as a thank-you for participating we will provide oral health supplies and reimbursement for public transit/parking up to a \$15.00 maximum (upon presentation of receipt). Also, as a result of the quick dental exam, we will give you a general idea about your/your son/daughter oral health status. Should the YASCHN have an urgent condition identified during this examination, we may be able to expedite emergency care through our connections in the dental community, especially if they do not have a dental home established.

#### What are the alternative ways to participate in the study?

You may choose to participate in a phone survey, without attending the dental clinic yourself/with your son/daughter. The investigator will audiotape and transcribe your response over the phone.

#### What happens if I decide to withdraw from the study?

You do not have to provide any reasons for your decision to withdraw from the study. We will retain any data collected up to the point of your withdrawal from the study.

#### How will your privacy be maintained?

Your confidentiality will be respected. No information that discloses your/your son/daughter’s identity will be released or published without your specific consent to the disclosure. All audiotape recordings will be stored on a password protected computer and external network for two years from the date of collection, then, they will be all destroyed. All documents will have a code number, not a name, and will

be stored in a locked filing cabinet. During the study period, only the principal investigator and the co-investigator will have access to the research materials. However, research records and dental records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC Research Ethics Board for the purpose of monitoring the research. However, no records which identify you by name or initials will be allowed to leave the Investigators' offices.

Who do I contact if I have questions about the study during my participation?

The persons who may be contacted about the research, the Principal Investigator and Co-Investigator, are listed at the top of page 1 of this form.

Who do I contact if I have questions or concerns about my rights as a subject during the study?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

**Title of Research Project:** *“Dental care beyond BC Children’s Hospital: perspectives on the transition experience for young adults with special health care needs”*

Subject/Caregiver Consent to participate:

I acknowledge that the purpose of this study has been explained to me and that any questions that I have asked have been answered to my satisfaction.

- I have been informed that I have the right not to participate and the right to withdraw. I also understand the benefits (if any) of participating in this survey.
- I know that I may ask now, or in the future, any questions I have about the study or the research procedures.
- I have been assured that records relating to my/my son’s/daughter’s care will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law.
- I also understand that I do not waive any of my legal rights by signing this consent form.
- I am aware that I will receive a signed and dated copy of this consent form.

I \_\_\_\_\_ (Subject/Caregiver PRINTED NAME) hereby consent to participate as a subject or primary caregiver of the subject of \_\_\_\_\_ (Subject’s NAME PRINTED).

I wish to be informed about the results of the study      YES      NO      (please circle)

I give my permission for the study team to contact me in future should clarification of any information be necessary      YES      NO      (please circle)

Signature of Subject/Caregiver: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Investigator/Designate (PRINTED): \_\_\_\_\_

Signature of Investigator/Designate: \_\_\_\_\_

**B.4 Survey**

Dental care after BCCH

Quick Survey

Subject ID: \_\_\_\_\_

Date: \_\_\_\_\_

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**1. How would you describe the condition of her/his/your teeth?**

- Excellent
- Good
- Fair
- Poor
- Don't know

**2. During the past 12 months, did she/he/you see a regular/family dentist?**

- Yes:  
Dentist's name: ..... City: .....
- No. skip to question no. 5

**3. Did she/he/you receive the dental care that she/he/you felt was needed?**

- Yes
- No
- Don't know
- 

**4. In general, how satisfied overall are you with her/his/your access to dental care?**

- Very satisfied
- Somewhat satisfied
- Somewhat unsatisfied
- Very unsatisfied
- 

**5. Why did she/he/you not see a regular/family dentist during the past 12 months OR not get the dental care that he/she needed?**

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