

# ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES IN ONTARIO: A FOCUS ON PERSONS WITH DEVELOPMENTAL DISABILITIES

by

Anjani Koneru DMD



A thesis submitted in conformity with the  
requirements for the degree of Master of Science  
Faculty of Dentistry  
University of Toronto

© Copyright by Anjani Koneru 2008

Anjani Koneru

ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES IN ONTARIO:  
A FOCUS ON PERSONS WITH DEVELOPMENTAL DISABILITIES

2008

Master of Science Degree

Faculty of Dentistry

University of Toronto

**ABSTRACT**

This study was undertaken to determine if persons with disabilities encounter difficulties in accessing dental care in Ontario, to identify barriers to accessing dental care and to determine if persons with disabilities and caregivers value oral health. Community organizations providing supports for persons with disabilities were recruited to circulate a questionnaire to their members via mail or internet. Fourteen community organizations mailed out 1755 paper questionnaires. A response rate of 23.9% was calculated from original surveys returned. In total, 634 paper and internet surveys were deemed valid. Data analysis was conducted using the chi square test and logistic regression. Most (73.2%) persons with disabilities, primarily developmental disabilities, were able to access dental services in Ontario. Personal internal factors were more likely to act as barriers to dental care than external factors. The majority of caregivers and persons with disabilities believe that oral health is an important part of overall health.

KEYWORDS: persons with disabilities, access to dental care, barriers

## ACKNOWLEDGEMENTS

Firstly, I would like to thank my thesis supervisor, Dr. Michael Sigal, for his insight and direction in making this project come to fruition. His dedication to improving dental care for persons with special health care needs is both heartfelt and inspiring.

Thanks also to Dr. Howard Tenenbaum and Dr. Peter Judd, for their help with editing the document. Their attention to detail was greatly appreciated.

Thanks also to Dr. David Locker for his assistance with managing the data and to Dr. Clive Friedman for his help with formulating the questionnaire.

I must also thank the many community organizations who provide services for persons with disabilities. Without the help of the following organizations, this project would not have been possible: Community Living Toronto, Community Living Ontario, Community Living Algoma, Community Living Owen Sound, Harmony Center for Community Living, Community Living Windsor, Community Living North Hastings, Community Living Thunder Bay, Community Living Oshawa/Clarington, Community Living Brantford, Community Living Superior Greenstone Association, Spina Bifida and Hydrocephalus Association of Ontario, Ontario Federation of Cerebral Palsy, Down Syndrome Association of Toronto, Down Syndrome Association of Ontario, Adult Protective Services Ontario, Epilepsy Ontario, Autism Partnership, Autism Ontario, Canadian Abilities Foundation, Geneva Center, Participation House.

Thanks to my classmates, Dr. Teresa Berger and Dr. Tracy Doyle, for their friendship and for making the past few years memorable.

Thanks to my loving husband Dr. Blayne Thibodeau for his humor and support, but also for encouraging me to always chase my dreams.

Thanks to my little brother Raghu Koneru, for keeping me on my toes and helping me to avoid IT disasters.

A final thank you to my parents Jhansi and Subhas Koneru for showing me the meaning of humility, charity and hope and that being a part of a community is a privilege.

## TABLE OF CONTENTS

ABSTRACT	ii
LIST OF FIGURES	vi
LIST OF TABLES	vii
INTRODUCTION	
DEFINITION OF DISABILITY	1
TYPES OF DISABILITY	3
PREVALENCE OF DISABILITY IN CANADA	4
PREVALENCE ON DISABILITY IN ONTARIO	6
DISABILITY IN ONTARIO: THE PAST	8
DENTAL CARE IN INSTITUTIONS: HISTORICAL PERSPECTIVE	11
DENTAL CARE IN THE COMMUNITY: HISTORICAL PERSPECTIVE	13
DISABILITY IN ONTARIO: THE PRESENT	14
DISABILITY SUPPORTS	16
CURRENT DENTAL CARE DELIVERY SYSTEMS IN ONTARIO	18
PAYMENT MECHANISMS FOR DENTAL CARE	19
ORAL HEALTH NEEDS OF PERSONS WITH DISABILITIES	24
ACCESS TO HEALTH CARE	26
ACCESS TO DENTAL CARE IN ONTARIO	27
ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES	29
ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES: CANADIAN STUDIES	34
RATIONALE	36
OBJECTIVES AND HYPOTHESES	37

## TABLE OF CONTENTS

METHODS	38
RESULTS	41
DISCUSSION	56
BIBLIOGRAPHY	78
APPENDIX A	88
APPENDIX B	89
APPENDIX C	90
APPENDIX D	94

## LIST OF FIGURES

Figure 1	Components of the International Class of Functioning, Disability and Health	2
Figure 2	Types of Disabilities in Ontario	6
Figure 3	Age Distribution of Persons with Disabilities	49
Figure 4	Gender Distribution of Persons with Disabilities	49
Figure 5	Geographic Distribution of Persons with Disabilities	50
Figure 6	Living Situation of Persons with Disabilities	50
Figure 7	Type of Disability or Condition	51
Figure 8	Type of Dental Coverage	51
Figure 9	Dental Appointment Frequency	52
Figure 10	Dental Appointment Length	52
Figure 11	Proximity to Dentist	53
Figure 12	Type of Dentist	53
Figure 13	Type of Dental Clinic	53
Figure 14	Types of Dental Treatment	54
Figure 15	Special Modifications for Dental Treatment	54
Figure 16	Barriers to Accessing Dental Care	55
Figure 17	Oral Health Important For Overall Health	55

## LIST OF TABLES

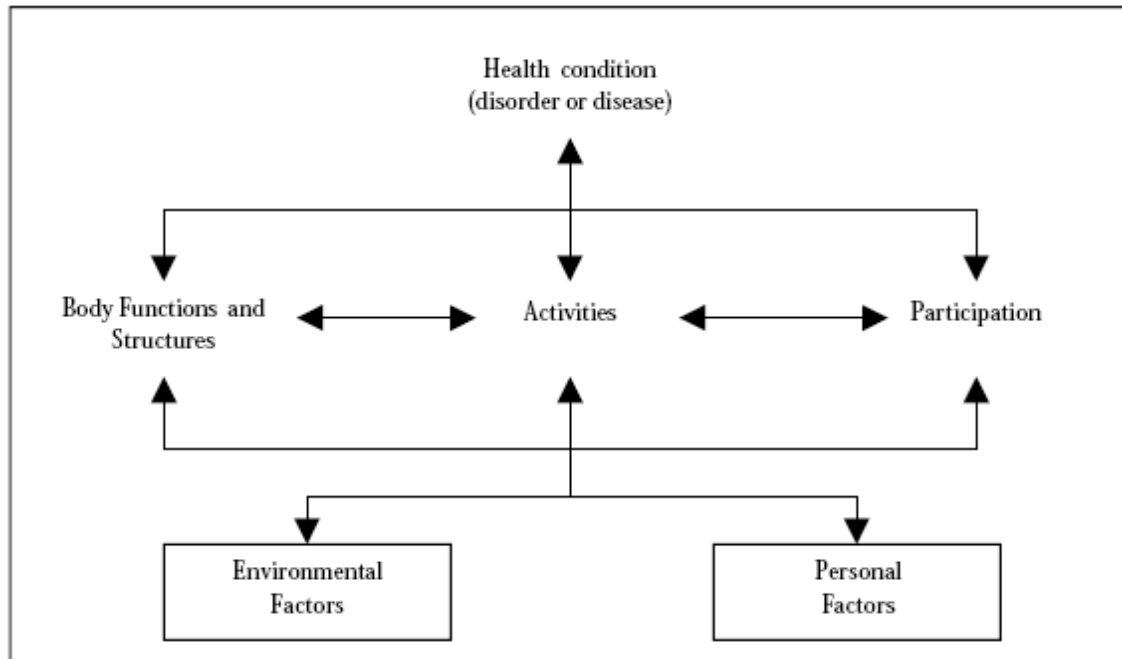
Table 1	Adults Using Developmental Services in Ontario.	17
Table 2	Factors Associated with Difficulty Accessing Dental Care	46
Table 3	Predictors of Difficulty Accessing Dental Care (Logistic Regression)	48

## INTRODUCTION

### DEFINITION OF DISABILITY

Disability is not well defined. Historically, a medical model was used to describe disability in terms of a physiological deficit in the disabled person. More recently a social model has emerged to define disability in terms of environmental barriers that prevent a person with a disability from functioning normally, subsequently leading to a negative impact on activities of daily living. In 2001, the World Health Organization adopted the International Classification of Functioning, Disability and Health (ICF). This model describes a more inclusive approach to the notion of disability by recognizing that disease and health can and should be framed within the context of 'biopsychosocial' parameters (Statistics Canada, 2001). The ICF framework looks at health in two parts, functioning and contextual factors (Perenboom & Chorus, 2003). Functioning and disability include the structure and function of the body and its effects on participation and daily activity. Participation is defined as involvement in or control of one's life situation, while activity is defined as the performance of a task or action (Perenboom & Chorus, 2003). Contextual factors include environmental and personal factors and can influence both participation and activity. This relationship is outlined in Figure 1 as described by the World Health Organization (WHO, 2001).

Figure 1. Components of the International Classification of Functioning, Disability and Health. (Source: ICF Introduction. World Health Organization 2001).



Using the ICF, the WHO describes disability as the outcome or result of a complex relationship between an individual's health condition and personal as well as external factors (World Health Organization, 2001). The Ontario Human Rights Code describes disability as any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect, or illness and without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, brain injury, any degree of paralysis, amputation, lack of physical coordination, blindness or visual impediment. The code also qualifies disability based on physical reliance on a guide dog or other animal, reliance on a wheelchair or other remedial appliance or device, a condition of mental impairment or a

developmental disability, a mental disorder, a learning disability, or a dysfunction in one or more of the processes involved in understanding, using symbols or spoken language. Persons who suffered an injury for which benefits were claimed or received under the Workplace Safety and Insurance Act 1997 are also considered to have a disability in Ontario (*Ontario Human Rights Code. R.S.O. 1990.c.H.19. 2006*). For the purpose of this discussion, a definition based on the British Disability Discrimination Act will be used; defining a person with a disability as a person who has or has had a physical, mental, or intellectual impairment causing a substantial and long-term adverse effect upon his or her ability to carry out normal daily activities that are typical for his/her stage of development and his or her cultural environment (Merry & Edwards, 2002).

#### TYPES OF DISABILITY

Activity and participation limitations arise from many types of disabilities. Disabilities may be related to hearing, vision, speech, pain, chronic conditions, mobility, agility or dexterity, learning, memory, psychological, and developmental or intellectual status. Disability can be 'visible' such as a physical impairment or 'non-visible' as exemplified by learning or memory deficits (Statistics Canada, 2007; see Appendix A and B for definitions of the types of disabilities). Disability can also change over time, being temporary or permanent in nature or entering periods of remission. Disabilities which enter remission however, have the potential for future exacerbations (HRSDC, 2006).

## PREVALENCE OF DISABILITY IN CANADA

It has been estimated that there are 4.4 million Canadians who have a disability, which represents at least 14.3% of the population (Statistics Canada, 2007). The number of people with disabilities is increasing due to population growth, increased reporting, an aging population and more accurate and sensitive methods for detection and diagnosis of disease and disability (Nunn, 1987; Waldman & Perlman, 2000; World Health Organization, 2006). In Canada 3.7% of children aged 0 to 15 years, 11.5% of youth and working-age adults (15 to 64 years), as well as 43.4% of seniors 65 and older have a disability. Over the age of 15, more women (17.7%) report disability than men (15.4%). Among Canadian children under 5 years old, disabilities are described in terms of general delays and chronic conditions, which differ from definitions of disability for adults (Statistics Canada, 2007). Disabilities due to chronic conditions are the most common disabilities among young Canadians, affecting about 1.2% of children aged 0 to 4 years and 3% of children aged 5 to 14 years. Examples of chronic conditions include but are not limited to asthma, complex medical conditions, cerebral palsy, autism, heart conditions, attention deficit disorders, and other long-term conditions. Delay (intellectual, physical, emotional delay) is seen in 1% of all children aged 0 to 4. As a child matures, observed delays are better classified into speech, mobility, agility, developmental, learning, or psychological disabilities. Developmental disabilities are seen in 1.4% of children aged 5 to 14 and learning disabilities are seen in 3.2%. Children with learning disabilities are greater in number than children with chronic conditions in the 5 to 14 year old age group. In

terms of number of disabilities or co-morbidity, 49.9% of young children aged 0 to 4 years with a disability have one type of limitation, while 41.2% have two types of limitations. In older children with disabilities (5 to 14 years), 26.3% have one type of limitation and 36.5% have two or three types of limitations, and 37.3% have 4 or more limitations. In terms of severity (based on intensity and frequency of activity limitations), 58.3% of children with disabilities who are in the 0 to 14 year old cohort have a mild-moderate disability and 41.7% have a severe or very severe disability. In total, 1.5% of all Canadian children aged 0 to 14 years have a severe or very severe disability (Statistics Canada, 2007).

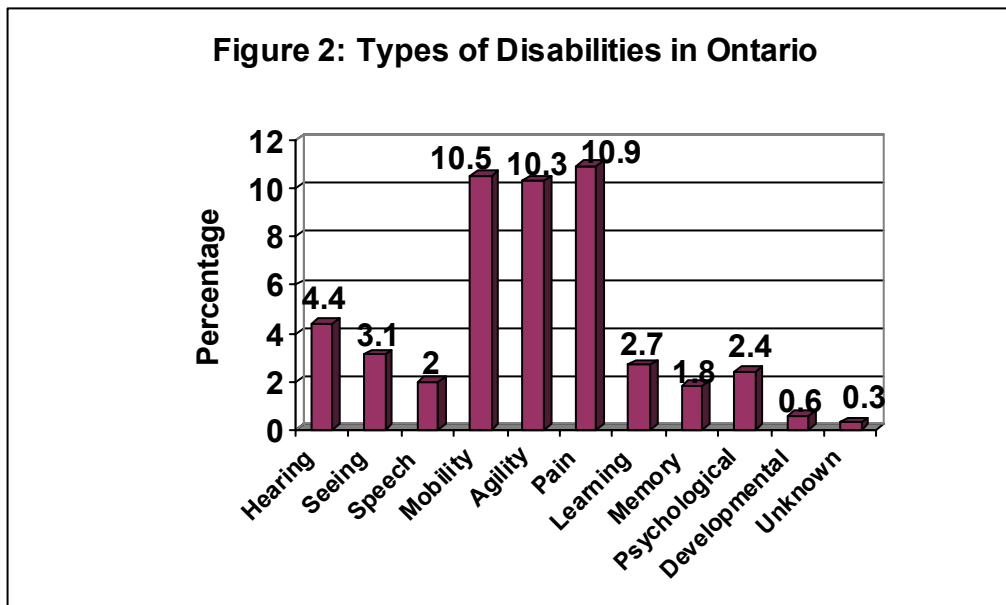
The most common disabilities affecting adults (aged 15 or older) relate to agility (11.1%), mobility (11.5%) and pain (11.7%). Nearly 70% of adult Canadians who have one of these disabilities report having the other two disabilities. The prevalence of co-morbid conditions in youth and adults (15 to 64 year cohort) is substantially higher than that observed in children. For example, 18.4% have one type of disability, 16.9% have two types, 27.9% have three types, 28.9% have four or five types and 8% have six or more types of disabilities. With regard to the severity of disabilities in this age group, 35.4% have mild disabilities, 24.8% have moderate disabilities, 26.3% have severe disabilities and 13.5% have very severe disabilities. In general, women report more severe disabilities than men. The prevalence and severity of disabilities appears to increase with age for most types of disabilities, such as mobility, agility, hearing, vision, pain, memory and speech. Older working adults aged 45 to 64 years are more likely to have psychological disabilities than seniors aged 65 to 74 years. This change may be related to work-

related stress that disappears at retirement. Severity of disability appears to increase until age 65, but then begins to decline slightly. In general, 6.6% of Canadians aged 15 and over have a severe or very severe disability (Statistics Canada, 2007).

#### PREVALENCE OF DISABILITY IN ONTARIO

In Ontario about 15.5% of the population has a disability, which represents approximately 1,853,570 people (Statistics Canada, 2007). Nearly four percent (3.8%) of Ontario children aged 0 to 14 years, 12.6% of youth and adults aged 15 to 64 years, and 47.2% of seniors 65 and older have a disability. The types of disabilities seen in Ontario are shown below in Figure 2 (Statistics Canada, 2007).

Figure 2. Types of Disabilities in Ontario. (Source: PALS Survey, Statistics Canada, 2007).



In Ontario, the most common types of disability are related to pain, mobility and agility. The least prevalent disability is the developmental type with only 1% of Ontario's population having an intellectual disability (Balogh, Oullette-Kuntz, & Hunter, 2004). A poll of non-institutionalized physically handicapped persons in Ontario (carried out in 1982) revealed that 13.0% perceived the primary cause of their disability to be hereditary, 6.8% congenital and 36.1% of unknown origin. Other reasons for disability were illness (13.1%), aging (6.2%), accidents (16.6%), and environmental causes (8.1%) (*Survey of non-institutionalized physically handicapped persons in Ontario: Socio-demographic and need-related characteristics*. 1982). The most common types of disability were similar in 1982 being mainly musculoskeletal, followed by cardiovascular and neurological. The Ontario Health Survey in 1990 stated less than 15% of Ontarians had a minor to major impairment in functioning (*Ontario health survey, 1990 : Highlights*. 1992). The 2000 Report on the Health Status of Residents of Ontario showed that the prevalence of disability ranged from 7% in Toronto to 12% in northern communities (*Report on the health status of the residents of Ontario*. 2000). More long-term disability was found in people with limited education and lower income. Forty percent of adults with disabilities had a post-secondary education, compared to 48% of the non-disabled population. The unemployment rate for persons with disabilities was 26% compared with 5% for adults without disabilities. Average income from all sources for persons with disabilities was \$22,543 compared with \$34,144 for non-disabled Ontarians. Eighty-four percent of women and 65% of

men with disabilities reported annual incomes of less than \$30,000 (MCSS, 2007a).

## DISABILITY IN ONTARIO: THE PAST

People with disabilities especially developmental disabilities have had an inspiring history in Ontario, being traditionally regarded with ignorance, fear and hopelessness until the mid 1800s (Williston, 1971). People with cognitive deficits were often left to their own devices, either isolated in family homes or incarcerated in jails. Ideas about 'curing' people with mental retardation by education and training based on models developed by Europeans Itard and Seguin were brought to Canada in the mid 1800s (Zarfes, 1976). Ontario's first place for people with developmental disabilities had its origins in the Old York Jail in 1841, which later transferred its inmates to a new facility in 1850 at 999 Queen Street, Toronto (Williston, 1971). This facility was called the 'Provincial Lunatic Asylum'. In 1859 a hotel in Orillia was converted into the 'Convalescent Lunatic Asylum' which closed and was later reopened in 1876 as Canada's first hospital training school for "feeble-minded" children and was called the 'Hospital for Idiots and Imbeciles' (Williston, 1971). What began as a developmental approach in the 1870's became a custodial charity approach by the 1900s. Funding was reduced and remained low until well after the Second World War. As a result, educational and vocational programming suffered. The idea that 'mentally retarded' people need to be protected from society (and vice-versa) prevailed and thoughts that such people were more likely to develop into criminals led to large numbers of 'mentally

retarded' people being grouped into large institutions (Hodgins, 1919). Fears that 'retarded' people would propagate and take over the world led to males and females being segregated. Emphasis was placed on work colonies in the hopes that these institutions would be self-supporting. Persons with intellectual disabilities were deprived of comforts and many amenities because of fears of delinquency. As of the early 1960s politicians ran the institutions in Ontario, controlling who was admitted regardless of need. Institutions ultimately became faced with overcrowding, understaffing and a lack of adequate financing (Zarfas, 1976). Parent associations were formed to try to improve conditions within institutions and to pressure education boards to allow children with intellectual disabilities into schools. The Special Classes Act was passed in 1911 permitting local school boards to set up classes for children with intelligent quotients over 50 but who were "backward and abnormally slow in learning" (Anglin & Braaten, 1978). For other children, in 1951 a parent run school was opened out of Carlton Street United Church in Toronto. In 1953, the Ontario Association for the Mentally Retarded (OAMR) was formed officially which strived to offer community based educational programs for people with intellectual disabilities. In the late 1950's and early 1960's, the Ontario government recognized the value of these schools and gradually increased financial support to local associations. In Ontario, the Disabled Persons' Allowance Act was passed in 1960, six years after the federal government had passed the Disabled Persons Act (1955) to compensate provincial governments for providing comprehensive programs to disabled people (Duhamel, 1963). In 1964 a federal and provincial conference was held on mental

retardation. With the assistance of the OAMR, the “Blueprint for Mental Retardation Programming in Ontario” was formed (Zarfas, 1976). Restructuring of the government occurred and educational programs for people with special needs now fell under the Ministry of Education. The institutions now went away from a medical model, to a more social learning model. A push for community residences was created. In 1966 the Homes for Retarded Persons Act was passed to provide financial assistance to community residences. Also in 1966 the Vocational Rehabilitation Act was passed to further expand sheltered workshops and training programs. In 1971 Walter Williston was commissioned by the Ontario Department of Health to report on the care and supervision of mentally retarded persons in Ontario. He noted a lack of central coordination between various government ministries. Based on his report, the government was restructured such that the diagnosis, assessment and counseling responsibilities for people with intellectual disabilities was transferred from the Ministry of Health to the Ministry of Community and Social Services (MCSS). The transfer of responsibility to the Ministry of Community and Social Services led to cost sharing with the federal government under the Canada Assistance Plan. The intellectually disabled adult who had less than \$1500 of personal resources and lived in a “home for special care” but needed services now qualified for support. Also under the Ministry of Community and Social Services, the Mental Retardations Services branch was formed and became responsible for supervising 19 institutions. The Mental Retardation Services established the Community Services Development Program to create services in the community to meet the needs of people with mental retardation. In

1974 the Development Services Act was brought into law, giving Ontario for the first time, a policy to reduce the number of provincial institutions in favor of bringing people with disabilities home (Hargreaves, Levine, & Atkins, 1976). The government's goal was to reduce facility population by 50% in 5 years. In the 1970s, 6000 residents lived in institutions (MCSS, 2007b). Now, only three of the original 19 institutions remain and are planned to close by the year 2009. These are the Rideau Regional Centre, Huronia Regional Centre and Southwestern Regional Centre (MCSS, 2007b).

#### DENTAL CARE IN INSTITUTIONS: HISTORICAL PERSPECTIVE

In terms of oral health issues for the 'mentally and physically handicapped', all dental care for long term residents in government owned and operated (Schedule I) facilities was covered by the Ministry of Health. When patients required exceptional services that could not be provided by institutional dental staff they were referred for treatment in the community (upon approval by the Ministry of Health). The province did not accept responsibility for dental treatment of outpatients (Gardner, 1972). Cost for dental treatment in government funded but privately run (Schedule II) facilities were borne by the local operating board and parents. The standard of dental care in Schedule II facilities was poor as these facilities did not have basic equipment to allow for dental examination, which made it difficult to find dentists to treat their residents. In addition, many dentists were reluctant to accept persons with disabilities into their private practices because of inadequate compensation if additional time and effort was needed to treat such

patients (*Status report on the report of the task force on community dental services for the mentally retarded and physically handicapped, September 1980*. 1980).

While nearly all Schedule I institutions had some basic dental services, general anesthesia facilities were limited, present only at the Hospital for Sick Children (Toronto), Ontario Crippled Children's Centre (Toronto), Scarborough General Hospital, and The War Memorial Children's Hospital in London (Gardner, 1972).

In institutions, medical and nursing staff provided routine health examinations, vision and hearing examinations, tuberculosis control, immunizations, and administration of medications (Zarfas, 1976), but other residential staff were not trained to provide basic oral hygiene services to their residents. Many of the staff themselves did not appreciate the benefits of maintaining good oral health (Gardner, 1972). According to the Williston report, Ontario's hospital schools were understaffed with respect to dentists (Williston, 1971), and yet a large number of people with intellectual disability who entered these institutions were in great need of dental treatment. Raising a child with intellectual disability was costly due to social and medical problems, and so parents often overlooked the dental needs of their children. Many parents as well as medical staff may have perceived oral health care as a luxury instead of as a necessity for overall health. Consequently, some institutions emphasized tooth extraction rather than tooth repair. Williston commented that this would affect how people with intellectual disabilities would adjust socially when they returned to their communities, because of self-esteem issues (Williston, 1971).

## DENTAL CARE IN THE COMMUNITY: HISTORICAL PERSPECTIVE

As persons with disabilities transitioned from institutions to community settings, dentists were often left out of the planning process. It was not until 1974, that a task force under the guidance of Dr. Norman Levine was created to study the provision of dental care to the 'mentally and physically handicapped' persons living in the community (*Overview of the task force report*. 1980). Based on the task force recommendations, the Ontario Health Insurance Plan (OHIP) began paying for in-hospital general anesthesia fees and hospital stays for dental treatment. Also, a roster of dentists willing to treat persons with disabilities was created. Government institutions were mandated to treat persons with disabilities who were unable to secure dental services in their communities. Public health units were recruited to carry out preventive dental programs in their catchment areas. A task force report in 1980 (*Status report on the report of the task force on community dental services for the mentally retarded and physically handicapped, September 1980*.1980) provided insight into the access of dental care for people with disabilities based on a survey of parents, clients, hospitals, homes and field workers. Most parents indicated they had a family dentist, but only 50% said their family dentist looked after their disabled child. While two-thirds of parents did not let dental fees inhibit accessing dental care for their children, cost was still a concern. A high percentage of adults with disabilities did not visit the dentist on a regular basis other than for emergency care. Cost of dental care was a big concern for this population. Operators of Homes for Special care were responsible for paying for dental treatment, but in cases where the person with the disability had

funds, the person with a disability was charged for dental treatment (*Status report on the report of the task force on community dental services for the mentally retarded and physically handicapped, September 1980*. 1980). Sixty-two percent of hospitals that were polled did not have an oral surgeon on staff or a dental department. In terms of homes and responses from field workers, 50% of residents had not had a dental examination in the last 18 months and most of the dental treatment received was on an emergency only basis (*Overview of the task force report*. 1980).

#### DISABILITY IN ONTARIO: THE PRESENT

Most persons with disabilities now live in community settings. Community living may involve living with parents or relatives, in group homes, supported independent living, or in foster care. The MCSS currently funds community organizations to provide these residential supports (MCSS, 2006d). Group-homes offer 24 hour support for three to six adults with developmental disabilities who require supervision and assistance with activities of daily living. Foster care or the family-home program places an individual with a 'host family'. The host family provides support for the person with a developmental disability in exchange for payment from the community agency. Family-homes usually support one or two individuals. Supported independent living allows persons with disabilities to live on their own or with another person while receiving limited supports from a community agency. In this setting a person with a disability receives 6-10 hours of personal support per week to aid with activities such as meal preparation, household chores

and getting ready to go to work. Some persons with disabilities require care in long term care facilities due to the nature of their medical status and disability. Long term care facilities are the responsibility of the Ministry of Health and Long Term Care (*Opportunities and action: Transforming supports in Ontario for people who have a developmental disability*.2006).

Other supports funded by the Ministry of Community and Social Services (MCSS) include respite services, community participation supports, specialized services for people with special needs, special services at home and services for people in institutions (*Opportunities and action: Transforming supports in Ontario for people who have a developmental disability*. 2006). Respite services are available for caregivers to provide a break from caregiving duties to increase a family's capacity to care for a person with a disability. The MCSS and Ministry of Children and Youth Services (MCYS) currently fund five types of respite supports: Assistance for Children with Severe Disabilities (ACSD), Out-of-Home Respite supports, In-Home Respite supports, Special Services at Home and Enhanced Respite for Medically Fragile and/or Technology Dependent Children. Community participation supports provide people with developmental disabilities with daytime activities aimed at increasing independence and participation in community activities. Community participation supports include day supports, employment supports, vocational alternative supports and adult protective services. Day supports provide volunteer, life skills and recreational activities. Employment supports help people in work settings. Vocational supports prepare for and support people in the workplace for no remuneration or minimal contract wages. Adult

protective services provide advocacy and case coordination for people living more independently in the community. Special-Services-at-Home provides funding to families and individuals to purchase supports that cannot be provided in their communities. These supports may include family relief or support for personal development and growth (*Opportunities and action: Transforming supports in Ontario for people who have a developmental disability*. 2006). Community Networks for Specialized Care were created in 2005 to coordinate a cohesive range of community based specialized services for people with high care needs. The community networks for specialized care encompass four regions, northern Ontario, central Ontario, eastern Ontario and southern Ontario. A total of eight agencies are involved as leaders of these networks to improve access to specialized services (MCSS, 2006c).

## DISABILITY SUPPORTS

Disability supports exist in many forms. The supports may be aids or devices, homemaker services, home care services, attendant services, home modifications, transportation, skills development, access to information in multiple formats, or income supports (HRSDC, 2006). The Ontario government currently spends about \$1.35 billion a year on community supports for people with developmental disabilities. These services provide financial and social supports to approximately 39,000 adults, primarily through community-based organizations. In 2006 the provincial government indicated it will invest \$84 million in new funding for developmental services. Eleven million dollars will go to the Passport program

to support young adults in the transition from school to participation in community activities, \$12.5 million for special services at home, \$30.2 million to help the more than 370 community based agencies address operating costs, \$10 million to create 200 new residential spaces and \$20 million in permanent funding to allow agencies to provide long term care for 250 people. In addition, the Ontario government's Home of Your Own effort aims to create 55 more group homes, 245 supported independent living/family home spaces, and 90 specialized spaces for individuals with high care needs. These initiatives are proposed to create enough spaces in the community for the 1000 people residing in institutions who will be relocated by the year 2009 (MCSS News Release, May 2, 2006). Table 1 shows the number of adults currently using developmental services in Ontario (*Opportunities and action: Transforming supports in Ontario for people who have a developmental disability.* 2006).

Table 1. Adults using Developmental Services in Ontario. (Source: Opportunities and Action. Transforming Supports in Ontario for People who have a Developmental Disability. 2006)

Number of Adults Using Developmental Services			
Residential Services		Other Support	
Type	No. of Individuals	Type	No. of Individuals
Facility	1000	Day Programs & Recreation	16400
Group Homes	7500	Employment Supports	6300
Supported Independent Living	5500	Assessment & Counseling	18700
Family Home	1200	SSAH	6000
		Respite	4600
		Specialized Services	9900

## CURRENT DENTAL CARE DELIVERY SYSTEM IN ONTARIO

Health care in Ontario is under the jurisdiction of the Ministry of Health and Long Term Care (MOHLTC). Fourteen local health integration networks (LHINs) report to the MOHLTC. These local networks are responsible for planning, coordinating and funding local health services. Each of the LHINs are responsible for hospitals, psychiatric hospitals, community care access centres, community health centres, long term care centres, community support service organizations, and community mental health and addiction agencies located in their respective geographic regions. Community health centres (CHCs) are non-profit centres focused on primary health care and health promotion. CHCs may or may not offer dental services in their communities. There are 54 CHCs in Ontario. Community care access centres (CCACs) were established by the MOHLTC to provide access to government funded home and community services and long term care homes. Their goal is to enhance access to care. There are 42 CCACs in Ontario. Ontario has 211 hospital sites with 8 sites being private hospitals. The MOHLTC maintains responsibility for public health units, physicians, ambulances, laboratories, and provincial networks and programs. There are 36 public health units (PHUs), which are run by municipalities, but financed in part by the MOHLTC. These clinics offer health promotion and disease prevention. The PHUs do not charge a fee for dental treatment, providing care to low income children under age 18 and low income seniors. Like the CHCs, not all public health units offer dental services. The majority of dentists practice privately in the community and are not associated with local hospitals, CHCs, PHUs or other institutions. In Ontario, like the rest of

Canada, private dentists provide the majority of dental services. There are currently 7790 dentists licensed in Ontario, with nearly 1000 dental specialists (Royal College of Dental Surgeons of Ontario, 2005). In 2005, the dentist-population ratio was 57/100,000 (Canadian Dental Association, 2005a). The data show that 80% of the Ontario Dental Association's members practice in urban settings (Pratt, 1997). In 1974, about 1000 dentists had hospital privileges, representing almost 25% of dentists in Ontario at the time (Kucey, 1979). Now, 1400 dentists (nearly 18% of Ontario dentists) have hospital privileges in Ontario (Baird & Abate, 2000). Some university-affiliated teaching hospitals have dental departments. However, the trend over the past 10 years has been the closure of over 18 hospital dental clinics, creating inadequate operating room time for 53% of the 1400 dentists who provide hospital-based dental care. As a consequence of these closures, wait times for operating room appointments are currently in excess of 3 months (Baird & Abate, 2000).

#### PAYMENT MECHANISMS FOR DENTAL CARE

In 2005, \$9.2 billion dollars were spent on dental care in Canada (Canadian Dental Association, 2005b). Dental care is not a covered service under the Canada Health Act. Many payment methods exist for remuneration of dental services in Ontario, falling under the categories of out of pocket expenses, private insurance (nearly 65% of Ontarians have dental insurance) and government sponsored programs (Millar, 2004; Stevens & Sinton, 2001). Over the past 20 years,

government-sponsored programs have been created to improve access to dental care (Farrell, 2001).

Children in Need of Treatment (CINOT) was created in 1987 to ensure that children under the age of 14 or until their last day of grade 8 are able to receive essential and emergent dental care despite limited financial resources and a lack of dental insurance. Children are screened by public health units at schools to identify children with oral pain, trauma, pathology, infection and dental caries. The screening process relies solely on visible findings and does not include radiographs. Parents of eligible children sign a declaration claiming that they do not have dental insurance or adequate dental insurance and that paying for their children's dental care will cause financial hardship. The coverage is valid for six months from the time the CINOT claim form is issued. CINOT was designed to treat current dental problems on a one-time only basis and is not to be considered dental insurance for providing ongoing care. Eligible children are able to seek the care of any Ontario dentist for restorative treatment, but preventive services are only provided through local public health units. The cost of CINOT is shared between the municipalities and the MOHLTC.

In 1998, the Ontario government created the Ontario Works (OW) and the Ontario Disability Support Program (ODSP). These programs replaced general welfare assistance and the family benefits program, respectively. The Ontario Works program, funded by the MCSS and local municipalities, provides both income and employment assistance for people in temporary financial need (MCSS, 2006b). The amount of financial assistance provided depends on housing costs

and family size. All OW recipients must be Ontario residents, have financial need and be willing to participate in employment assistance programs. Some recipients may be eligible for drug and dental coverage, eyeglasses, and hearing aid benefits. OW dental benefits provided to adults (aged 18 years and over) have been until recently, discretionary and limited to emergency dental services. In the fall of 2007, the Ontario government allocated \$45 million dollars to provide basic dental services for low income working adults without private insurance (Benzie, 2007). Dependents (aged 0 to 17 years) of OW recipients are entitled to basic dental coverage allowing routine dental examinations and dental treatment. Aside from OW and CINOT, some municipalities have their own programs. Ottawa's Employment and Financial Assistance Branch runs a special program called Essential Health and Social Supports. This program provides essential health services like dental care and vision care to low-income individuals not eligible for OW and ODSP through Ottawa's city clinics (EFA, 2007).

The Ontario Disability Support program, funded by the MCSS, provides income supports and employment supports to people with disabilities in financial need or in need of support to work (MCSS, 2006a). Income support provides financial assistance and other benefits to persons with disabilities and their families. Income support is meant to cover accommodation, basic living expenses, prescription drugs and basic dental care. Basic dental care includes diagnostic and preventive procedures, fillings, root canals and extractions. Additional benefits include eyeglasses, hearing aids, special medical supplies, transportation costs to attend medical appointments, clothing allowances, start-up benefits, mobility

device repairs, home repairs and guide dog allowances. Eligibility for ODSP includes Ontario residency, the presence of a long term disability and financial need. Ontarians who receive disability benefits under the Canada Pension Plan or who are over age 65 and not eligible for Old Age Security (OAS) can qualify for ODSP coverage. Other eligible persons are those who live in a psychiatric facility, who live in a facility under the Development Services Act or in a home under the Homes for Special Care Act. Persons who are about to turn 18 and previously received the ACSD benefit may also qualify for the Ontario Disability Support Program. The ODSP provides coverage of basic dental services to the person with the disability and their dependents under the age of 18. Certain dental procedures require prior approval and some are limited by time and frequency. The Ontario Dental Association (ODA) has managed social assistance dental claims since 1958. In March 2001, the ODA set up AccertaClaim Servcorp Inc. (Accerta) to take over dental claim processing. Accerta is owned by the ODA, but operated independently (Glasgow, 2005). Accerta processes all ODSP claims, but are contracted by municipalities to process OW claims. Some municipalities such as Toronto, do not use Accerta, instead choosing to process OW claims on their own.

Assistance for Children with Severe Disabilities (ACSD) is another program which provides financial support to families with children who have special needs (MCYS, 2007). Financial assistance may range from \$25 to \$400 depending on the family's gross annual income and number of children. Children under this program are eligible for dental benefits. Children under the age of 18 who live at home with a parent or legal guardian, who have a severe disability that causes a

functional loss, or who incur extraordinary cost due the nature of their disability may qualify for the program. This program is administered by the Ministry of Children and Youth Services (MCYS).

The Ontario Cleft Lip and Palate/Craniofacial Dental Program provides financial assistance for the specialized dental needs of people affected with craniofacial anomalies caused by certain conditions (MOHLTC, 2007). To be eligible for this program, clients must be residents of Ontario, be diagnosed with a cleft lip or palate or craniofacial anomaly and be registered in the program prior to their 18th birthday. This program will reimburse 75% of dental treatment costs for those who have no dental insurance, and 75% of what remains after private dental insurance is applied. A \$15,000 limit applies to non-orthodontic treatment for persons with eligible conditions. The program does not cover the cost of routine dentistry or long term follow-up care. The designated paymaster for this program is the Hospital for Sick Children in Toronto and funding is provided by the MOHLTC. Last of provincial programs is the Ontario Hospital Insurance Plan (OHIP), also funded by the MOHLTC. OHIP covers in-patient services and out-patient hospital services such as operating room use and anesthesia costs (Baird & Abate, 2000). OHIP also covers certain surgical dental procedures.

Aside from provincial programs, federal programs exist to provide access to dental care. One such program is Non-Insured Health Benefits (NIHB) provided by Health Canada through the First Nations and Inuit Health Branch (FNIHB). These benefits are provided to registered First Nations and Inuit people in Canada to cover the cost of non-insured health services under the Canada Health Act. As of

March 2005, Ontario had 164,716 eligible First Nations persons and Inuit. \$29.7 million was spent in Ontario on NIHB benefits in 2004/05 (*Non-insured health benefits program 2004-2005 annual report*. 2005). In the NIHB program, dentists bill First Canadian Health. NIHB covers diagnostic, preventive, restorative and oral surgery procedures. The program also covers orthodontic treatment and sedation. The program requires prior approval for certain procedures and also has time and frequency restrictions.

Other federal programs include the Interim Federal Health Program (IFHP), workers compensation and the Department of Veteran Affairs. The Interim Federal Health Program provides essential and emergency dental services to new immigrants to Canada (Citizenship and Immigration Canada, 2001). Once emergency care is provided, a treatment plan with radiographs can be submitted to outline treatment for the most affected teeth. Non-urgent treatment requires prior-approval. In urgent cases, a two teeth treatment maximum per visit is waived. Workers Compensation is financed by workplace taxes and covers income and rehabilitation services for work-related injury or illness. Workers compensation pays for dental treatment needed as a result of workplace injuries. The Department of Veterans Affairs provides dental benefits for veterans in Ontario and throughout Canada (Veteran Affairs Canada, 1999).

## ORAL HEALTH NEEDS OF PERSONS WITH DISABILITIES

Previous studies that examined the dental needs of persons with disabilities noted the incidence of caries to be similar to non-disabled populations (Brown,

1980; Hennequin, Faulks, & Roux, 2000), however persons with disabilities had higher rates of untreated dental disease and greater numbers of extracted teeth (Allison, Hennequin, & Faulks, 2000; Tiller, Wilson, & Gallagher, 2001). Most of the data concerning the prevalence of oral diseases in persons with disabilities are scattered, relying on parental reports and findings from specific population groups (Crall, 2007). The existing body of knowledge reveals that oral hygiene is generally poorer in persons with disabilities, making them more susceptible to periodontal disease (Brown, 1980). Unmet dental treatment needs may be related to poor access to dental care, or improper diagnosis. Accurate diagnosis is often difficult to accomplish in persons with disabilities who have a limited ability to express pain or describe their symptoms. Some persons with disabilities may also be unable to cooperate with the dentist during clinical assessment appointments such that thorough dental examination, radiographic assessment and diagnosis cannot be performed. In some cases, dentists may choose not to be proactive and treat, instead choosing to monitor caries (Hennequin et al., 2000). The treatment of dental caries in many persons with disabilities often leads to dental extraction of otherwise restorable teeth, a problem compounded further by many persons with disabilities only seeking dental care on an emergency basis. Failure to achieve comprehensive, timely dental care creates a significant treatment backlog leading to increased treatment costs (Brown, 1980; Tesini & Fenton, 1994). Regular preventive oral health care can improve the health of persons with disabilities with little effort and great long term benefit (Brown, 1980; Tesini & Fenton, 1994). The overall costs to the patient, the dentist and society are reduced significantly over

time and issues like access to care for difficult procedures such as restorative dental treatment are precluded (Brown, 1980; Tesini & Fenton, 1994).

#### ACCESS TO HEALTH CARE:

One in five Canadians report difficulty accessing medical services for themselves or a family member. In Canada 23.2 million (94%) people over the age of 15 accessed first contact services (routine care, health information, immediate care for a minor problem) over a 12 month period in 2001 (Sanmartin, Houle, Berthelot, & White, 2002). Nearly 4.3 million people had difficulty obtaining care. The most common reasons for difficulty obtaining care, during regular office hours (9 a.m. to 5 p.m.), were difficulty getting an appointment (42.1%), long waiting times (33.2%), long in-office waits (20.3%), difficulty contacting a physician (13.1%), unavailable services (9.6%), lack of a regular family physician (4.8%), transportation problems (0.7%), and other reasons (13%). In general, 11% of Canadians experienced unmet health needs, similar to 11.2% of Ontarians (Sanmartin et al., 2002). When questioned why they had unmet needs, these people cited reasons such as long waiting times (49.4%), unavailable services (36.6%), fear (2.2%), transportation problems, being too busy (3.7%), not knowing where to obtain care (1.4%), not attempting to obtain care (3.1%), and 15.9% had other unspecified reasons (Sanmartin et al., 2002). As unmet health needs can be interpreted as a measure of access to care, it is interesting to note that personal factors seem to affect whether a person reports unmet needs. Kasman & Badley, 2004 suggest people are more likely to report unmet health needs when they

perceive the system has failed them rather than because of difficulty accessing services. Persons with severe health problems are more likely to report dissatisfaction with health services than persons without health problems (Iezzoni, Roger, Soukop & O'Day, 2002).

Persons with disabilities face similar barriers to accessing medical care such as shortage of medical personnel (especially in rural areas), transportation problems, cultural and language barriers, and long waiting times. Possible additional barriers are physicians who are unprepared to treat persons with developmental disabilities, attitudinal barriers, and environmental barriers. It appears that persons with disabilities are able to obtain medical care with more ease than they can obtain dental care. Dental care is still referred to as an unmet health need for this population (Reichard, Sacco & Turnbull, 2004).

#### ACCESS TO DENTAL CARE IN ONTARIO

Access to dental care is defined as the ability to obtain or make use of dental care (Guay, 2004). Utilization of dental care in Ontario has improved over the last thirty years. In 1990 two-thirds of Ontarians saw the dentist once or more per year, but 45% of people with primary education and 57% of people with low incomes did not. Unlike barriers to medical care, the major barriers to accessing dental care are related to financial difficulty. Frequency of dental visits was related strongly to not only income and education, but also to having dental insurance as demonstrated by the fact that 78% of people who had dental insurance saw the dentist within the past year as compared to 50% without dental insurance. People

living in the north also had fewer dental visits with 45% not seeing the dentist in the past year. In general, low-income earners were less likely to have dental insurance and therefore were less likely to see the dentist (*Ontario health survey, 1990: Highlights*.1992). In 1999 the second report on the health of Canadians found that 71% of Ontarians had seen a dentist in the past year, but that people in the north were once again less likely to see a dentist as compared to people living in other regions (Advisory Committee on Population Health (ACPH), 2000). In general, young people or families with low income levels did not have health benefits, factors that probably had a negative impact on access to dental care. In this regard, only 48% of people in the aforementioned cohort, visited the dentist over the past year (Johnson, Goettler, Goral, Leffley, & et al., 2000). Overall however, as of 2003, it was reported that 69.3% of Ontarians saw a dentist in the past year (Canadian Dental Association, 2005c).

Other barriers to accessing dental care are dental anxiety or phobia, transportation problems, shortage of dental personnel in certain areas, availability of services (sedation, general anesthesia), ignorance, attitudes and cultural and language issues (OPHA, 2005). Oral health status shows a strong association with education level, race, ethnicity, and income. In Ontario, persons of aboriginal descent or persons born outside of Canada experience poor oral health compared with the rest of Canada's population (Lawrence & Leake, 2001).

## ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES

Most people with disabilities live in their communities in family homes, foster homes or group homes (Burtner, Jones, McNeal, & Low, 1990; Waldman & Perlman, 2001). A few people still require long-term care facilities due to the nature of their disability or the presence of an underlying medical condition (McDermott & El-Badrawy, 1986). Normalization has provided persons with disabilities with a better home-life, but at the same time made them more reliant upon health services in their communities (Waldman & Perlman, 2001). Persons with disabilities and their caregivers must now actively seek dental care (Kaye, Fiske, Bower, Newton, & Fenlon, 2005) and a great onus has been placed upon community healthcare providers to meet their needs.

Studies addressing access to dental care for persons with disabilities have been inconsistent. Many studies differ in establishing the ease or difficulty experienced by persons with disabilities in obtaining dental care. Some studies show that 35-80% have had no difficulty accessing care while others show 50-70% have had difficulty (Al Agili, Roseman, Pass, Thornton, & Chavers, 2004; Bourke & Jago, 1983; Burtner et al., 1990; Finger & Jedrychowksi, 1989; McDermott & El-Badrawy, 1986; Russell & Kinirons, 1993). These inconsistencies may be due to many factors, some of which might be attributed to the relative affluence of the persons with disabilities polled or even the geographic location of the people surveyed relative to their proximity to dental services (Bourke & Jago, 1983). In regard to persons with disabilities and their caregivers who claim great difficulty in obtaining dental care, numerous reasons have been cited in the literature for this

disparity. Barriers to care may be manifested by issues described as the availability of dental care, proximity to dental clinics, financial difficulties, psychological and health disabilities that prevent routine care and legal issues such as consent and guardianship. Other barriers to care may be related to dental apathy and ignorance. Some persons with disabilities may experience no barriers, while others may experience multiple barriers depending on their personal situation (Tesini & Fenton, 1994).

Issues relating to the availability of dental care are due to the fact that some dentists will not treat persons with disabilities for reasons of increased time, cost, lack of adequate training or lack of suitable facilities. Survey studies carried out twenty years ago found that only 20% of dentists were willing to treat persons with disabilities (Kamen, 1981), while more recent studies report that 80-90% of dentists treat persons with disabilities (Oliver, C.H. Nunn, J.H., 1996; Seigal, 1985). In the province of Ontario, 89% of general dentists and 100% of pediatric dentists indicated that they are willing to treat persons with disabilities (Loeppky & Sigal, 2006). Some dentists have claimed that extra time is needed to treat persons with disabilities (Burtner et al., 1990), while others conjecture that this is not always the case (D. O'Donnell, 1996; Tesini & Fenton, 1994). Treatment time is patient dependent. Not all persons with disabilities fit one stereotype and some may in fact be easier to treat than persons without disabilities (D. O'Donnell, 1996). Dental practice management seems to be the most likely limiting factor in terms of treating persons with and without disabilities efficiently (Lawton, 2002; Steifel, 1981).

It has been reported that most persons with disabilities are able to be seen in private dental office settings, with minor modifications if any (Waldman & Perlman, 2002) and so the lack of adequate facilities for the management of such patients is more of a misperception by dentists rather than a true barrier. Proximity issues however, such as geographical and transportation issues, can be a true challenge to accessing care (Bourke & Jago, 1983; McDermott & El-Badrawy, 1986; Tesini & Fenton, 1994). It is not uncommon for persons with disabilities and their caregivers to contact many dentists because a local dentist will not treat them or accept government reimbursement (Al Agili et al., 2004; Braff, 1985; S. J. Fenton, Hood, Holder, May, & Mouradian, 2003; Persson, Stiefel, Griffith, Truelove, & Martin, 2000). If a person with a disability actually finds a dentist who is willing to treat him or her, the dental clinic may be far away making it difficult to obtain the necessary transportation required to visit the dentist. This is a critical shortcoming since 27% of adults with disabilities cannot travel long distances, some cannot use public transport (HRSDC, 2006), and the cost of taxis is expensive, in which case, persons with disabilities often rely on others to bring them to appointments (Steifel, 1981). Financial factors that prevent persons with disabilities or their caregivers from taking time off work to attend dental appointments can be a significant barrier to accessing dental care (Finger & Jedrychowksi, 1989; Oliver, C.H. Nunn, J.H., 1996). Other financial barriers are a lack of dental insurance, inadequate dental insurance, low income or an inability to pay fees charged by dentists. It is common for persons with disabilities on government sponsored programs to report difficulty obtaining dental care (Al Agili

et al., 2004; Burtner & Dicks, 1994), whereas persons with disabilities who have the means to pay for dental treatment report better access (Finger & Jedrychowksi, 1989; Lo, Soh, Vignehsa, & Chellappah, 1991).

Psychological issues such as the attitudes of dentists, caregivers and persons with disabilities towards dental care can also impede delivery of care. The beliefs, priorities and fears of caregivers regarding dental treatment can be projected onto their charges, thereby either hindering or enabling persons with disabilities from obtaining dental care (Kaye et al., 2005). Some dentists might also have beliefs that make them unable to cope with treating persons with disabilities (D. O'Donnell, 1985). In addition, internal patient characteristics such as treatment cooperation (Al Agili et al., 2004), self image (Finger & Jedrychowksi, 1989), and dental fear and anxiety (Clark & Vanek, 1984; Gordon, Dionne, & Snyder, 1998) can significantly affect whether persons with disabilities will be interested or successful in receiving dental care. Persons with mental illness can have difficulty obtaining dental care because of the mental illness itself (Chalmers, Kingsford-Smith, & Carter, 1998). These people may have difficulty making and keeping appointments, or have difficulty waiting or sitting in the waiting room, especially if they have dental anxiety. Finally, there is a minority of people with disabilities who are uncooperative and unreceptive to sedation and gentle restraint who require general anesthesia to receive dental care (Hennequin et al., 2000). These people along with people with severe medical problems generally must be seen in a hospital setting, further restricting their limited access to care, because hospital

dental services are not as prevalent as private dental offices and usually have longer waiting lists.

Legal barriers to care, as mentioned before, revolve around the issues of informed consent and guardianship. Fears of violating the rights of persons with disabilities have led to increasing controversies (J. P. O'Donnell, 1994). Persons with disabilities have the right to refuse dental treatment if they are able to appreciate the situation and its consequences and able to manipulate information rationally (Shuman & Bebeau, 1994). Although a person with a disability may not be able to act independently, his or her need for informed consent is still valid. The use of restraint has come under scrutiny and remains a point of contention in regard to human rights. Many dentists do not feel comfortable getting involved in the putative legal controversies related to patient-restraint and may opt to not see persons with disabilities for this reason (J. P. O'Donnell, 1994).

Legal guardianship can be difficult to determine at times, but this determination is critically important since legal guardians are the final treatment decision makers for persons with disabilities deemed incompetent by the courts (Tesini & Fenton, 1994). Delivery of dental care becomes delayed when legal decision makers are not accessible for consultation and approval during dental appointments. It is very common for caregivers who are not qualified to make legal decisions on behalf of their charges to bring their charges to dental appointments (Steifel, 1981). Poor cooperation for accurate diagnosis further compounds the issue of informed consent for legally incompetent persons. Definitive treatment plans are not possible for these patients until the time of treatment, and changes to

treatment plans are the norm. Most legal guardians rely upon dentists to make treatment decisions in these situations and some dentists inadvertently end up in the cross-fire of disgruntled guardians (J. P. O'Donnell, 1994).

Needless to say, establishing an ongoing relationship with a dentist or a dental home can be quite difficult for persons with disabilities. However, despite these barriers, many persons with disabilities do access dental care. A common frustration for those who access dental care appears to be related to obtaining dental care in a timely fashion. Many persons with disabilities face long waiting lists and long waiting room times (Al Agili et al., 2004; Crall, 2007). Al Agili et al., 2004 found that 23% of their respondents had difficulty scheduling dental appointments, encountering waiting lists up to 6 months long. The same study found that 50% of the parents who had scheduling problems also reported waiting more than 15 minutes at the dental office. Thus even for those able to obtain dental care there may still be some underlying difficulties.

## ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES: CANADIAN STUDIES

Recent data regarding access to dental care for persons with developmental and intellectual disabilities in Canada are sparse. More than thirty years ago, in 1971, Kenny and Mckim reported that 25.9% of children with cerebral palsy and 15.5% of children with Down syndrome had difficulty obtaining dental care. In 1986, McDermott and El Badrawy looked at dental care for persons with disabilities, finding that parents were generally satisfied with the dental treatment

their children had received (McDermott & El Badrawy, 1986). More recently in 2004, Allison and Lawrence compared the dental care received by Canadian Down syndrome children with that of their non-Down syndrome siblings and found that children with Down syndrome received less active dental treatment than their siblings (Allison & Lawrence, 2004). Other recent studies have focused on the dental needs of the homebound and the elderly (Locker, 2001; Matear & Barbaro, 2006). Locker (2001) observed that the provision of dental services improved the oral health status of the elderly and Matear and Barbaro (2006) observed that most caregivers and family members believed that basic dental care was important for their elderly charges. It would be interesting to know if persons with disabilities, primarily persons with developmental disabilities, currently experience difficulty in accessing dental care in Ontario, and if these difficulties are related to failure of dental programs, the dental infrastructure or due to certain characteristics individual to persons with disabilities.

## RATIONALE

In 1974, dental treatment was the greatest unmet health need of handicapped persons (Hennequin et al., 2000). In 2000, the US Surgeon General stated that there are still large gaps in dental care access for persons with disabilities compared with the rest of Americans (DHHS, 2000), but this type of information is not readily available in Canada. Therefore, the proposed study will explore the current experiences of persons with disabilities and their caregivers in accessing dental care in Ontario.

## OBJECTIVES

1. To determine if persons with disabilities encounter difficulties in accessing dental care in Ontario.
2. To identify barriers to dental care should difficulty in accessing dental care exist.
3. To determine attitudes of persons with disabilities or their caregivers towards the importance of oral health as a component of overall general health.

## HYPOTHESES (H<sub>1</sub>)

1. Persons with disabilities experience difficulty accessing dental care in Ontario.
2. Persons with disabilities and caregivers of persons with disabilities in Ontario believe oral health is important.

## METHODS

Ethics approval was obtained from the Health Sciences Research Ethics Board at the University of Toronto on June 12, 2006. A literature review was conducted to identify current issues facing persons with disabilities in accessing dental care. A 19-item questionnaire (appendix C) was created out of this literature review and pre-tested amongst a group of persons with disabilities and their caregivers in London, Ontario. The questionnaire was also reviewed prior to its administration by a panel of experts with experience in providing dental care for persons with disabilities in Ontario. The questionnaire had four pages including a cover page and consisted of three sections: demographic information, dental experience information and oral health attitude information. In cases where the persons with disabilities were unable to complete the self-administered questionnaire, their caregivers were asked to answer the questions on behalf of their charges. The questions were both open and close-ended, relating to experienced barriers in accessing dental care and past dental history. A Likert scale was used to assess attitudes towards oral health. The self administered questionnaire was made available in paper and electronic/online formats. A sample size calculation was conducted for a power of 80% using the probability proportional to population size (PPS) method. The number of people in Ontario with disability was estimated at 1.5 million based on data available at the time (Statistics Canada, 2001). Sampling error was set at 5%. The confidence level that the findings in the sample accurately reflected the total disabled population in

Ontario was set at 95%. Assuming that only two outcomes for accessing dental care were possible, such as yes and no, the following formula was applied:

$$N_s = \frac{(N_p) (p) (1-p)}{(N_p-1) (B/C)^2 + (p) (1-p)}$$

$N_s$  = completed sample size needed for desired level of precision

$N_p$  = size of population

$P$  = proportion expected to choose one of the two overall response categories (50% no dental access, 50% have dental access)

$B$  = acceptable amount of sampling error 5% of the true population value.

$C$  = 1.96 (Z statistic corresponding to 95% confidence level).

Based on this formula, the sample size was determined to be:

$$\frac{1500000 (0.5) (0.5)}{(1500000-1) (0.05/1.96)^2 + (.5) (.5)} = 384$$

A sample frame could not be created due to a lack of a comprehensive list of persons with disabilities in Ontario. Instead, community organizations that provide services for people with disabilities were enlisted to participate in the study. The organizations were asked to advertise the study via email, phone, website, bulletin boards, newsletters and to also directly distribute paper questionnaires to their members. The organizations were asked to select every 'N'th person from their mailing list as a potential participant in the study. The

organizations mailed pre-assembled questionnaire packages containing the questionnaire, cover letter and self-addressed pre-stamped envelope to their selected members. The packages were sent out once. Follow-up reminder notices were not sent. The electronic-online questionnaire was hosted by the online company Zoomerang, Inc and accessible from the Faculty of Dentistry, University of Toronto's website and also from the websites of participating community organizations. The electronic questionnaire was completed and submitted online.

One hundred twenty one organizations were contacted asking for their participation in the study, of which 22 agreed to participate. Paper questionnaire packages, 1755 in total, were mailed by 14 community organizations between September 2006 and November 2006. Responses were accepted between September 2006 and January 31, 2007. The returned mailed and electronically submitted questionnaires were reviewed for completeness. Valid returned questionnaires were coded and entered into a Statistical Package for the Social Sciences (SPSS) 14.0 database. Geographic location was coded as western Ontario, eastern Ontario, northern Ontario, central Ontario and metropolitan Toronto. See appendix D for geographic location definitions. Data analysis consisted of simple frequencies and percentages of the responses. Comparisons and associations were explored using bivariate chi-square analysis, fisher's exact test and multivariate logistic regression.

## RESULTS

### RESPONSE

Ten of the 1755 questionnaire packages were marked 'return to sender', but 420 paper questionnaires were completed and returned by mail. The response rate was 23.9%. In addition to the original paper questionnaires returned, 101 participants had printed their own paper copies of the survey and mailed them in, and 135 participants completed the questionnaire online. An overall response rate could not be tabulated for the additional paper and online questionnaires because a denominator could not be determined. Out of 656 returned questionnaires, 22 were considered invalid due to missing pages and the fact that a disability was not identified, leaving 634 valid surveys available for data analysis.

### RESPONDENTS

Completed questionnaires were returned by 484 caregivers on behalf of a person with a disability. The persons with disabilities represented by caregiver responses will be referred to as the CG-PWD group. The majority of the caregivers in the CG-PWD group (60.4%) were between the ages of 35 and 64, while 8.1% were under age 35, and 6.8% over age 65. Nearly 25% of caregivers did not report their age and 13% did not report their gender. The majority of the caregivers were female (72.3%), while 14.7% were male. One hundred and fifty persons with disabilities completed the questionnaire on their own. These individuals will be referred to as the PWD group. The persons with disabilities in the CG-PWD group tended to be younger than the PWD group (see Figure 3 for age distribution in

both groups). Persons with disabilities in the CG-PWD group were mostly male (53.3%) whereas the PWD group was mostly female (59.3%), (Figure 4). The majority of the persons with disabilities lived in metro Toronto (46.7%), while the fewest lived in northern Ontario (8.7%), (Figure 5). The majority of the persons with disabilities in the CG-PWD group, lived in parental or guardian homes (53.7%), followed by group homes (39.9%), and independent living situations (4.8%). The self-reporting PWD group indicated that 57.3% lived in independent or supported living situations, 21.3% lived in parental, guardian or family homes and 12.7% lived in group homes (Figure 6). The majority of the persons with disabilities in the CG-PWD group had developmental delay (41.3%), 30.2% had Down syndrome, 9.6% had autism, while 19% had other types of conditions. Nearly 30% (29.6%) had 2 or more conditions. The PWD group self reported that 37.3% had a developmental disability, 4.4% had autism, 6.1% had Down syndrome, while the rest 52.8% (94) had some other type of condition (Figure 7). Five percent of the PWD group had two or more conditions. ODSP was the most common type of dental coverage (62.4%), followed by private insurance (21.7%) and no insurance (6.1%). A small minority (8.2%) had a combination of more than one coverage type. Other types of dental coverage such as OW, NIHB, ACSD or funding from MOH in long-term care facilities were less common (1.6%), (Figure 8).

Ninety one caregivers (18.8% of caregivers) completed the questionnaire online, compared to 43 (28.7%) of the self-reporting persons with disabilities. Common characteristics amongst the online respondents were having a disability, being older than age 25, living central Ontario or metropolitan Toronto and living

independently or with support. The types of disabilities reported most often by the online respondents were autism, Down syndrome, a physical disability, epilepsy, moderate developmental delay or another type of condition such as stroke, head injury, or psychiatric illness ( $p < 0.05$ , chi-squared test).

## DENTAL EXPERIENCE

Four hundred and twenty three (87.4%) of the persons with disabilities in the CG-PWD group had seen a dentist within the past year, and 116 (77.3%) of the PWD group had self-reported a similar frequency. Most persons with disabilities (41.9%; pooled data) saw the dentist every 6 months, while the minority saw the dentist at greater than one year intervals (1.8%) and 5.5% saw the dentist only on an emergency basis (Figure 9). Three hundred and seventy five (77.5%) persons with disabilities in the CG-PWD group had dental needs which required treatment. Ninety seven (64.7%) of the PWD group reported having similar dental needs. Almost half (47.1%) of the CG-PWD group had difficulty communicating dental pain, whereas only 17.3% of the PWD group reported having difficulty.

On average, times spent for dental appointments were similar for both groups as 61.8% of the CG-PWD group and 62.7% of the PWD group spent less than 30 minutes with a dentist and up to 1 hour for a visit to see both a dental hygienist and dentist (Figure 10). Nearly half (49.6%) of the persons with disabilities in the CG-PWD group reported living within 10 km of a dentist. This number was similar for 54.7% of the PWD group (Figure 11). Most of the persons with disabilities (73.6%) saw a general dentist, but persons with disabilities in the

CG-PWD group were more likely to see a specialist (30.8%) than the persons with disabilities in the PWD group (8.0%), (Figure 12). Persons with disabilities (pooled data from both groups) were seen most often in a private dental clinic (71.6%), followed by hospital clinics (20.7%) and public health clinics (7.6%). Caregivers reported that 67.4% of their charges frequented a private clinic, 23.6% attended a hospital-based dental clinic and 6.8% went to a public health unit. Most self-reporting persons with disabilities (77.3%) indicated they went to a private dental clinic, whereas 9.3% attended a hospital-based clinic and 9.3% attended a public health unit (Figure 13). Most of persons with disabilities (pooled data from both groups) had received dental examinations (94.7%), radiographs (79.4%), cleanings (90.7%), oral hygiene instruction (39.4%), fillings (62.5%) and extractions (47.8%). A lesser proportion of persons with disabilities had received major restorative treatment or other dental therapy such as endodontic treatment (11.8%), crowns (4.1%), implants (1.9%), orthodontic therapy (12.0%), bleaching (1.3%) and sealants (11.3%). However, those in the CG-PWD group were less likely than those in the PWD group to have undergone endodontic therapy, bleaching, and non-stainless steel crowns (Figure 14).

The majority of the persons with disabilities from both groups, nearly 51%, did not require special modifications to receive dental treatment (Figure 15). Twenty six percent of persons with disabilities in the CG-PWD group needed general anesthesia and 25.4% needed sedation. The PWD group was more likely to need a wheel chair transfer (19.0%) than the CG-PWD group (7.6%). Sixteen percent of the PWD group needed sedation, 11.6% needed general anesthesia

and 4.8% needed a special chair with a back rest or head rest supports. The use of protective support or restraint was similar for both groups (5%). Nine percent of the CG-PWD group and 8% of the PWD group reported needing other modifications such as antibiotic prophylaxis, music, the presence of caregivers or staff in the dental treatment room, and the empathetic demeanor of the treating dentist.

#### ACCESS TO DENTAL CARE

A similar proportion of the CG-PWD group (74.2%) and the PWD group (70%) did not have difficulty accessing dental care. The most common barriers to accessing dental care cited by the caregivers on behalf of their charges and the self-reporting persons with disabilities were fear of the dentist (17.5%), an inability to cooperate with treatment (18.9%), cost (16.4%) and transportation difficulties (10.7%), (Figure 16). Other barriers that were identified based on open-ended responses were the limited coverage of the Ontario Disability Support Program (ODSP), the lack of acceptance of ODSP by dentists, the presence of major medical problems overriding dental problems, the lack of information about dental clinic locations and dentist attitudes towards treatment planning for persons with disabilities.

Difficulty accessing dental care was associated with many factors in both the CG-PWD and PWD groups (Table 2). A significant association was found in both the CG-PWD and PWD group between difficulty accessing dental care and difficulty communicating pain and needing special modifications to receive dental

treatment. In the CG-PWD group, a diagnosis of Down syndrome or severe developmental delay, caregiver age over 25, and living in western Ontario were associated with greater difficulty accessing dental care. Upon further exploration, caregiver age over 45 did not show a significant association with difficulty accessing dental care, but caregiver age over 55 did show an association. Type of dental coverage was also found to be a factor as persons with disabilities in the CG-PWD group who only had private dental insurance or sole dental coverage provided by a government organization had greater difficulty accessing dental care than people without coverage, or with other combinations of different types of dental coverage ( $p < 0.05$ , chi square test). Respondents in the PWD group experienced significant difficulty accessing dental care if they lacked dental coverage, or had a diagnosis of autism ( $p < 0.05$ , chi square test).

Table 2. Factors Associated with Difficulty Accessing Dental Care

Independent Factor	CG-PWD p value* (chi square test)**	PWD p value* (chi square test)**
Caregiver Age (over age 25)	0.046	N/A
Caregiver Age (over age 45)	0.089	N/A
Caregiver Age (over age 55)	0.005	N/A
PWD Age (over age 25)	0.644	0.600
Caregiver Gender	0.400	N/A
PWD Gender	0.756	0.214
Autism	0.061	0.039
Down Syndrome	0.034	0.374
Cerebral Palsy	0.794	0.872
Spina Bifida	0.242	0.443
Epilepsy	0.945	0.586

Independent Factor	CG-PWD p value* (chi square test)**	PWD p value* (chi square test)**
Physical Disability	0.782	0.771 (Fisher's Exact Test)
Mild Developmental Delay	0.652	0.794
Moderate Developmental Delay	0.398	0.586
Severe Developmental Delay	0.001	1.000 (Fisher's Exact Test)
Developmental Delay (Unspecified Severity)	0.276	0.202
Other Condition	0.356	0.218
Living Situation	0.851	0.248
Difficulty Communicating Pain	0.001	0.014
Need Special Modifications for Dental Treatment	0.001	0.001
Living in Northern Ontario	0.063	0.432
Living in Eastern Ontario	0.639	0.133
Living in Western Ontario	0.005	0.603
Living in Central Ontario	0.087	0.061
Living in Metro Toronto	0.959	0.912
No dental insurance or dental coverage	0.819	0.038
Private Insurance Only	0.004	0.115
Government Coverage Only	0.021	0.566
Private and ODSP coverage	0.847	0.584 (Fisher's Exact Test)

\*p value < 0.05 considered statistically significant

\*\* chi square test unless otherwise specified.

Statistically significant predictors of the CG-PWD group having difficulty accessing dental care, identified by logistic regression, were difficulty communicating dental pain, and a need for special modifications to receive dental treatment. For self-reporting persons with disabilities, significant predictors were a

lack of dental coverage, a need for special modifications to receive dental treatment, and a diagnosis of autism (Table 3).

Table 3. Predictors of Difficulty Accessing Dental Care (Logistic Regression).

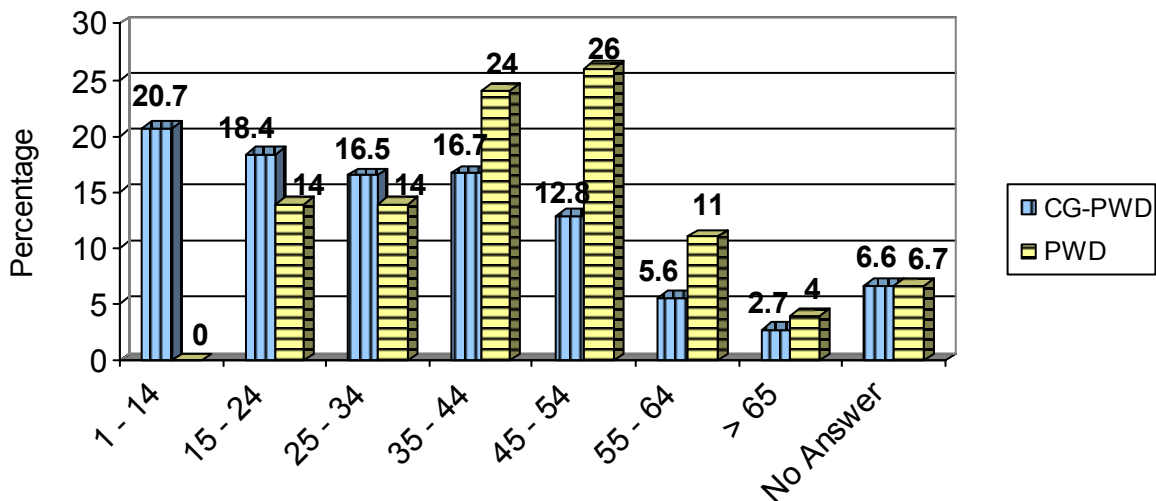
	Predictor	P value	OR	95% CI
CG-PWD	Difficulty communicating pain	0.020	1.98	1.12 – 3.51
	Requires special modifications	0.001	2.56	1.45 – 4.52
PWD	No dental coverage	0.032	3.32	1.11 – 9.91
	Autism	0.043	5.83	1.06 – 32.19
	Requires special modifications	0.001	5.23	2.31 – 11.81

OR = Odds Ratio; 95 % CI = 95% Confidence Interval

#### ORAL HEALTH AS AN IMPORTANT COMPONENT OF OVERALL HEALTH

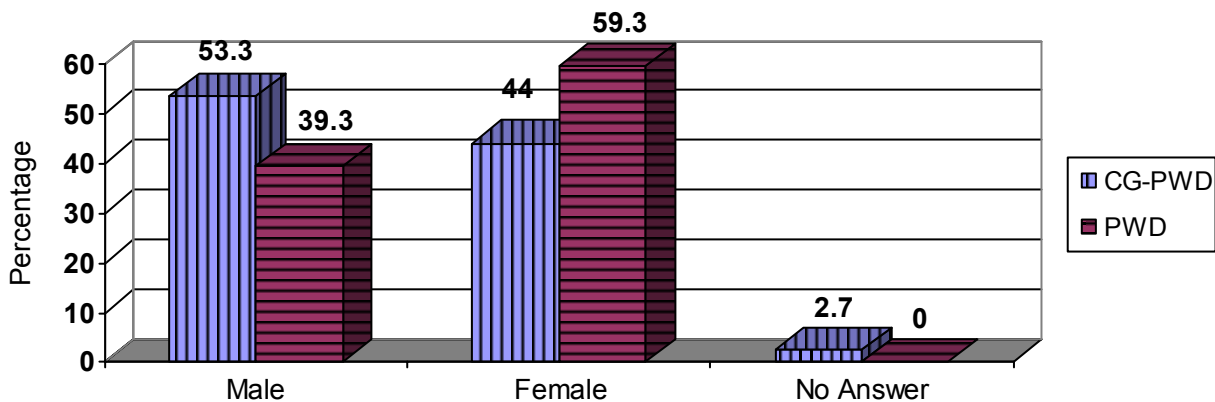
The majority of the caregivers who completed questionnaires on behalf of a person with a disability agreed (90.3%) or strongly agreed (79.3%) that oral health is important for general health. Similar agreement (24.7%) or strong agreement (66.0%) was seen amongst people with disabilities who completed their own questionnaires (Figure 17). No significant age or gender differences were displayed as nearly 90% of males and females of all ages felt oral health was connected to general health. No relationship was found between caregiver opinion or the opinion of persons with disabilities and access to dental care or dental visit frequency.

**Figure 3: Age Distribution of Persons with Disabilities**



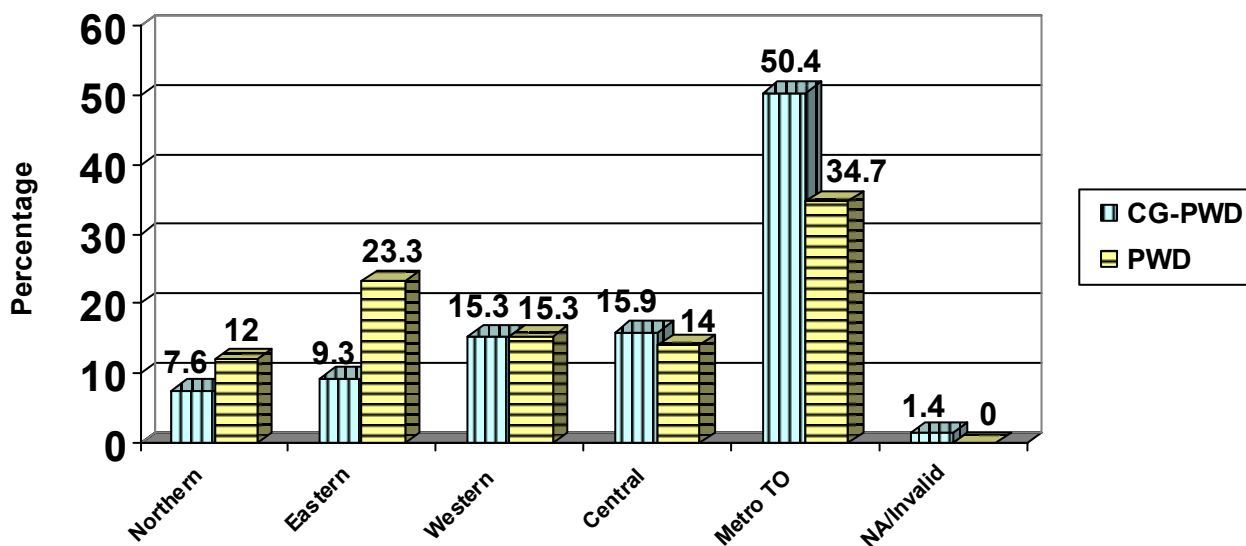
**Figure 3.** Persons with disabilities in the caregiver group (CG-PWD group) were younger than self-reporting persons with disabilities (PWD group).

**Figure 4: Gender Distribution of Persons with Disabilities**



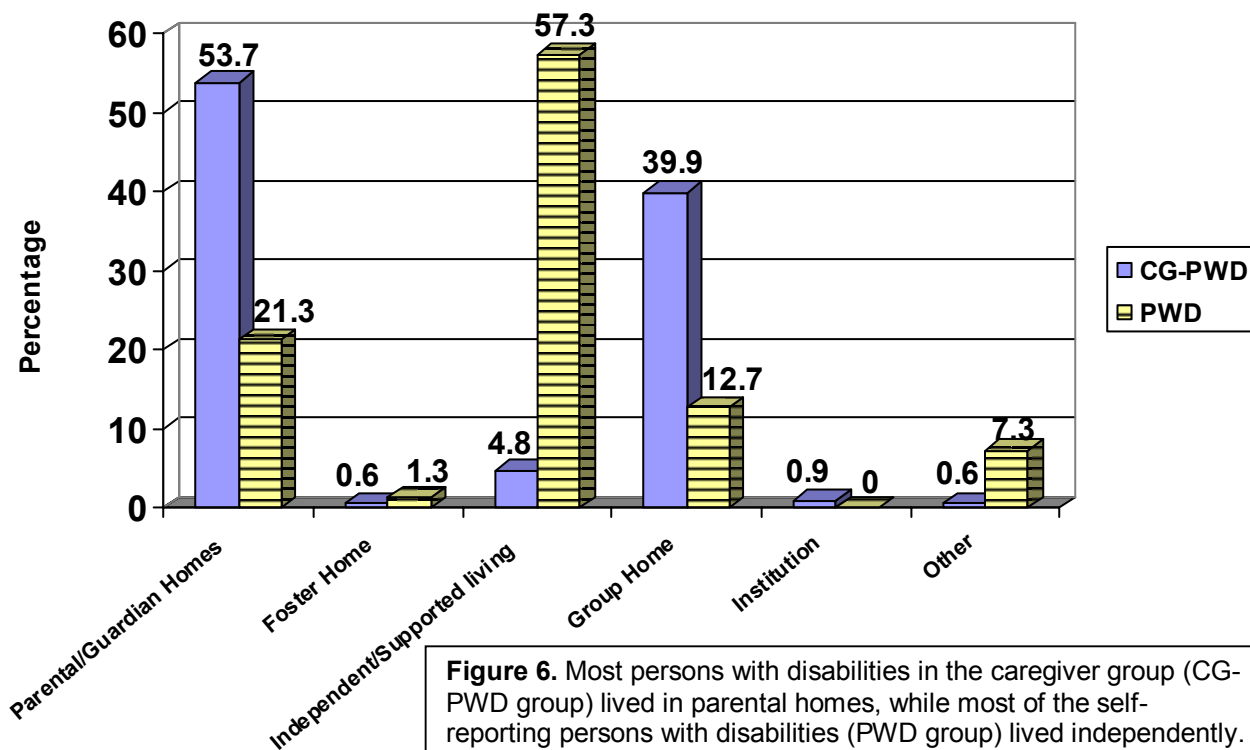
**Figure 4.** More persons with disabilities in the caregiver group (CG-PWD group) were male than female, while more self-reporting persons with disabilities (PWD group) were female.

**Figure 5: Geographic Distribution of Persons with Disabilities**



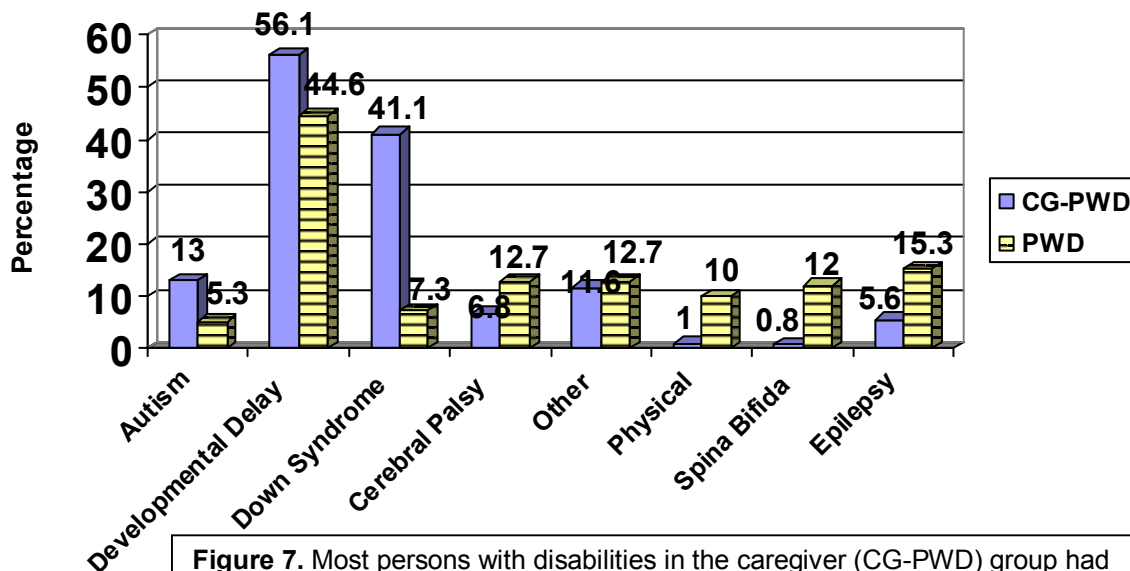
**Figure 5.** Most of the persons with disabilities in both groups lived in metropolitan Toronto, while the least lived in northern Ontario.

**Figure 6: Living Situation of Persons with Disabilities**



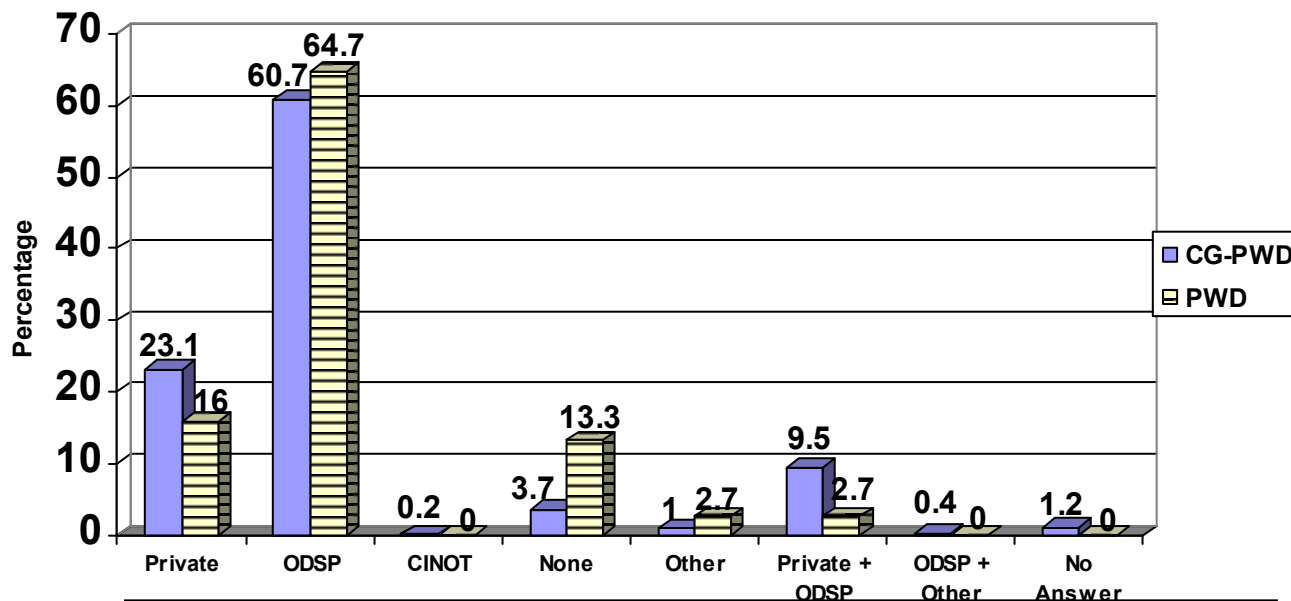
**Figure 6.** Most persons with disabilities in the caregiver group (CG-PWD group) lived in parental homes, while most of the self-reporting persons with disabilities (PWD group) lived independently.

**Figure 7: Type of Disability or Condition**



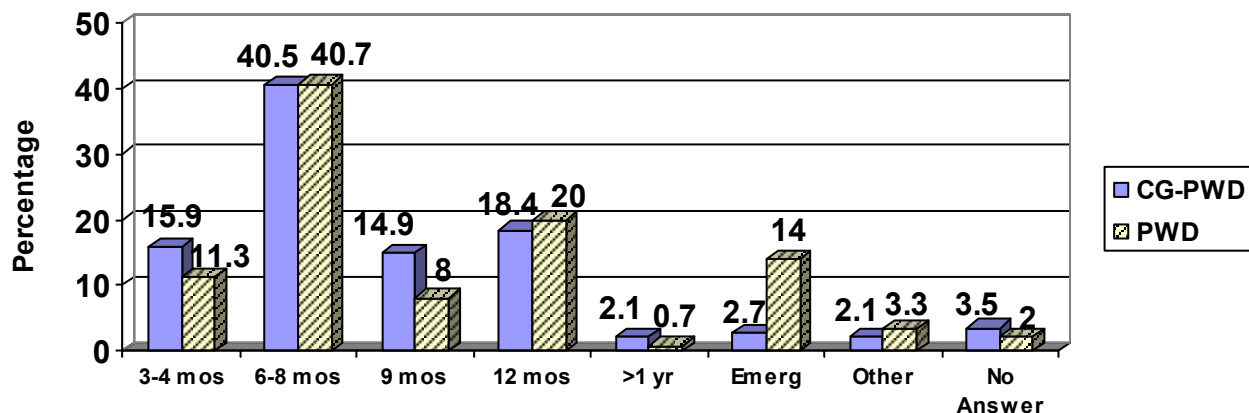
**Figure 7.** Most persons with disabilities in the caregiver (CG-PWD) group had intellectual disabilities compared to self reporting persons with disabilities who had mostly physical or psychiatric related disabilities.

**Figure 8: Type of Dental Coverage**



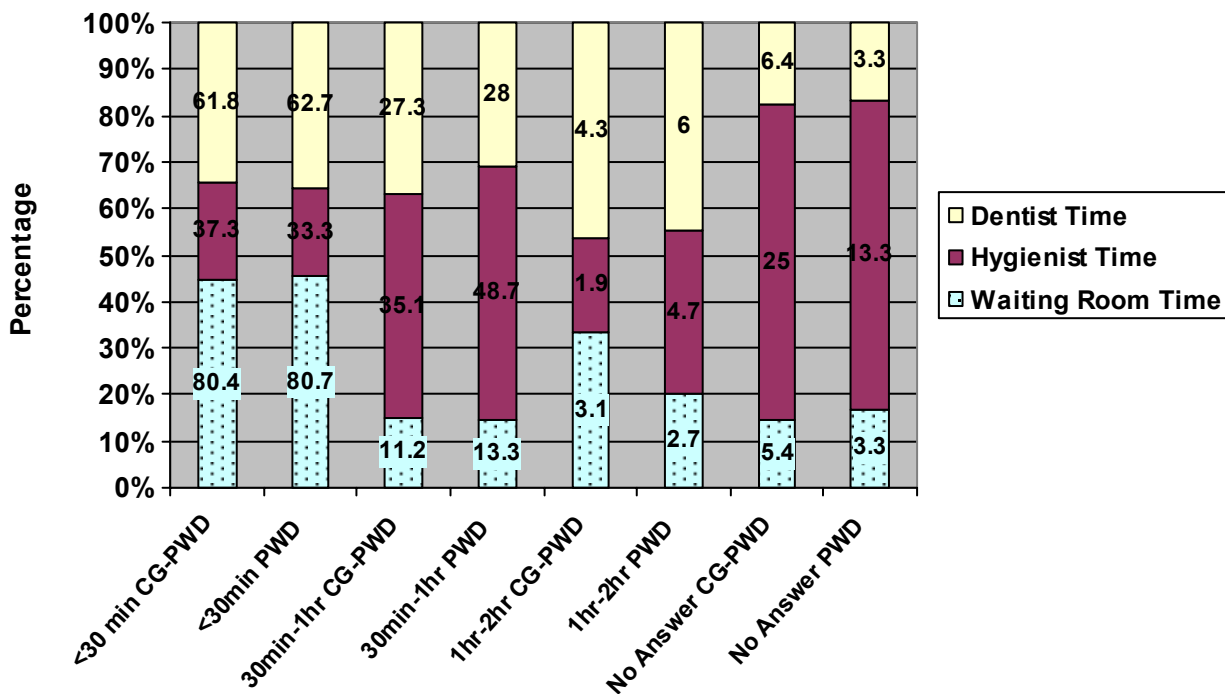
**Figure 8.** Most persons with disabilities had ODSP dental coverage. Self-reporting persons with disabilities (PWD group) were more likely to report no coverage than persons with disabilities in the caregiver (CG-PWD) group.

**Figure 9: Dental Appointment Frequency**



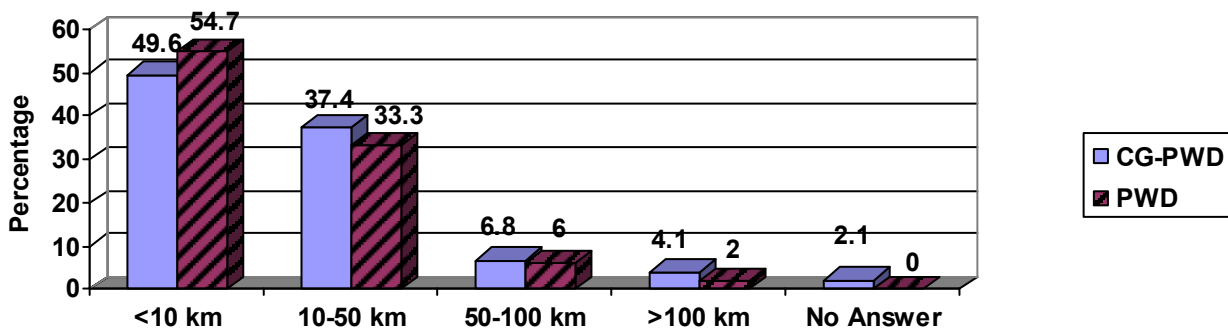
**Figure 9.** The majority of persons with disabilities see the dentist every 6 months.

**Figure 10: Dental Appointment Length**



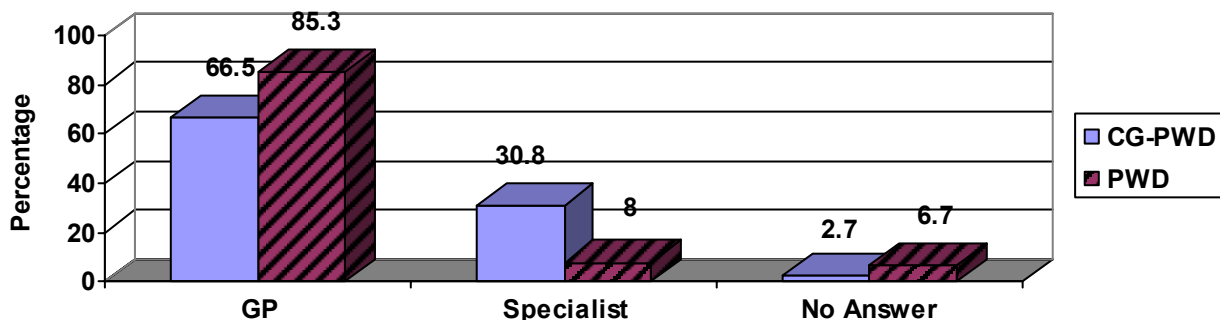
**Figure 10.** Most persons with disabilities spend less than 30 minutes in the waiting room at a dental clinic and upto1 hour with a dental hygienist. Average time spent with a dentist was less than 30 minutes.

**Figure 11: Proximity to Dentist**



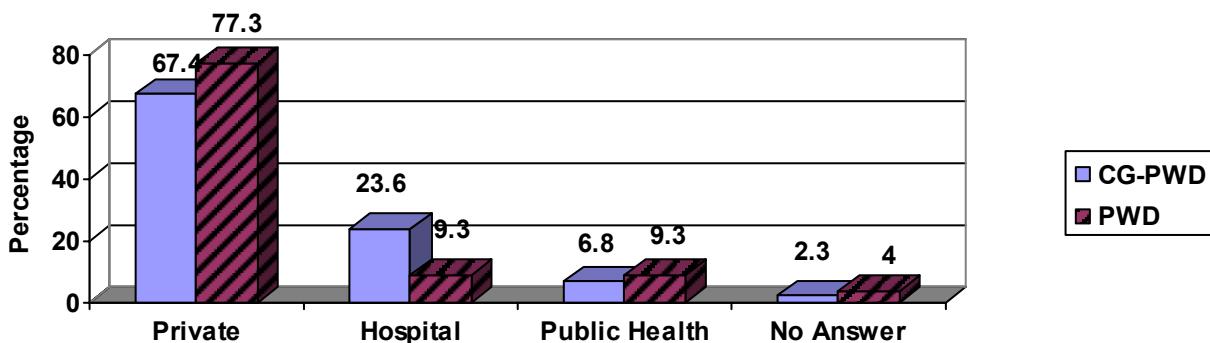
**Figure 11.** Most persons with disabilities live within 10km or 50 km of their regular dentist.

**Figure 12: Type of Dentist**



**Figure 12.** Most persons with disabilities are treated by general dentists, but more persons with disabilities in the caregiver (CG-PWD) group see dental specialists than in the self-reporting persons with disabilities (PWD) group.

**Figure 13: Type of Dental Clinic**



**Figure 13.** Most persons with disabilities attend private dental clinics, but more persons with disabilities in the caregiver (CG-PWD) group attend hospital clinics than in the self-reporting persons with disabilities (PWD) group.

Figure 14: Types of Dental Treatment

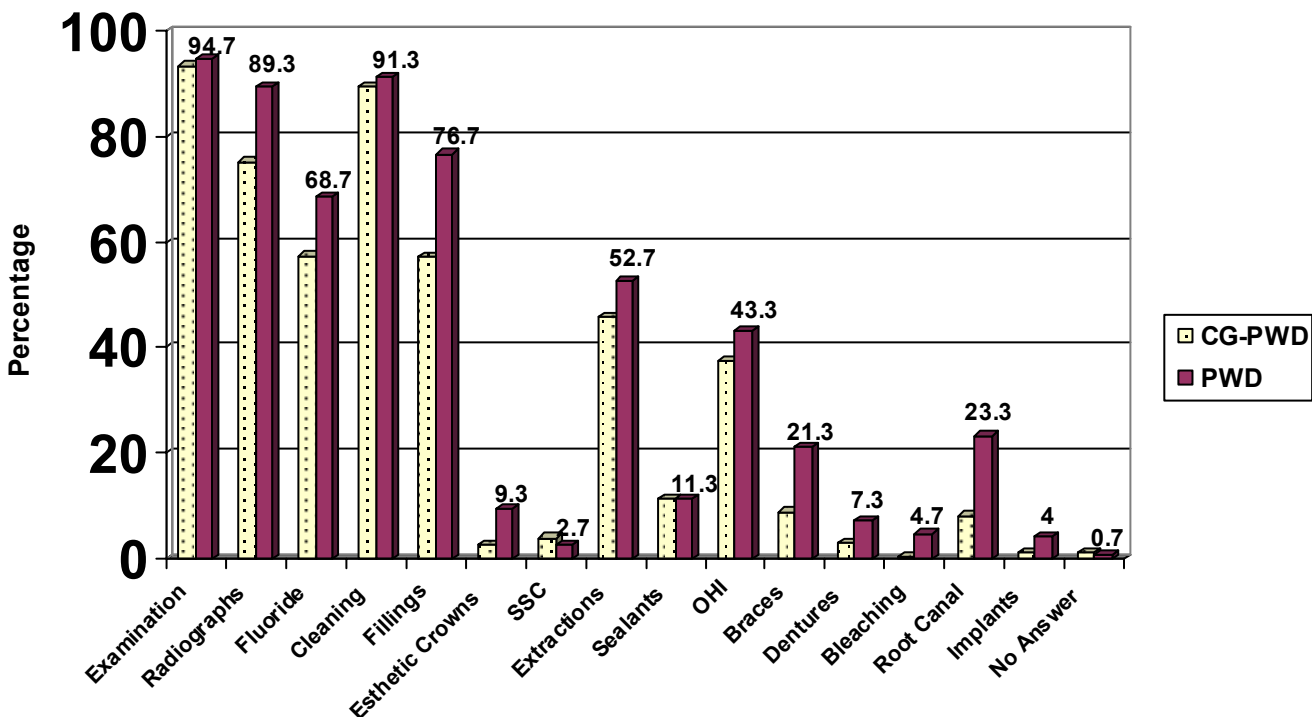


Figure 14. Most persons with disabilities have had diagnostic procedures as well as fillings and extractions. A smaller proportion have received root canal therapy, bleaching, implants or orthodontic therapy.

Figure 15: Special Modifications for Dental Treatment

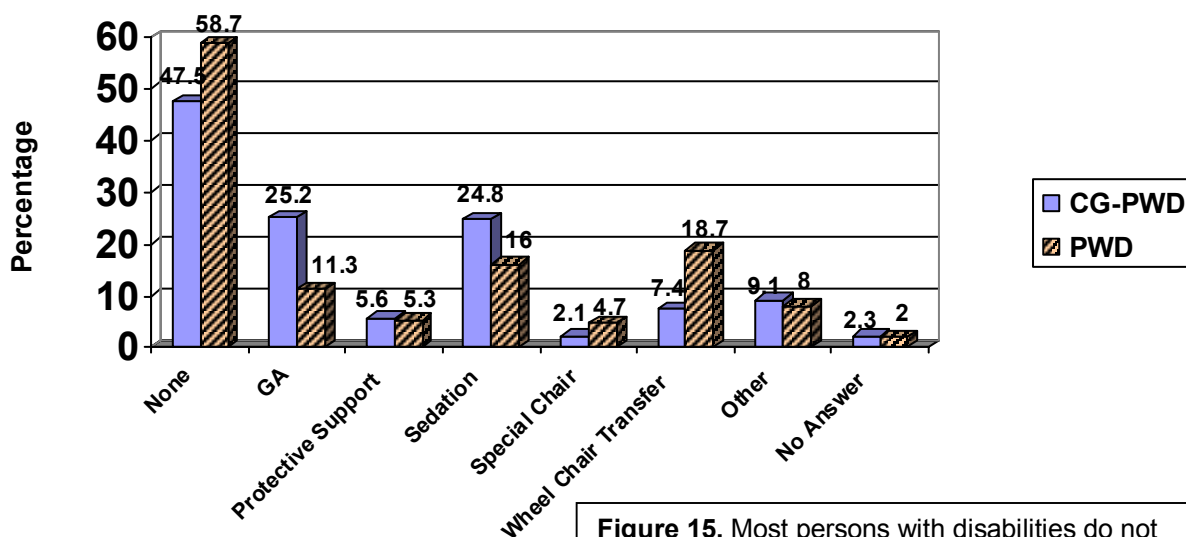
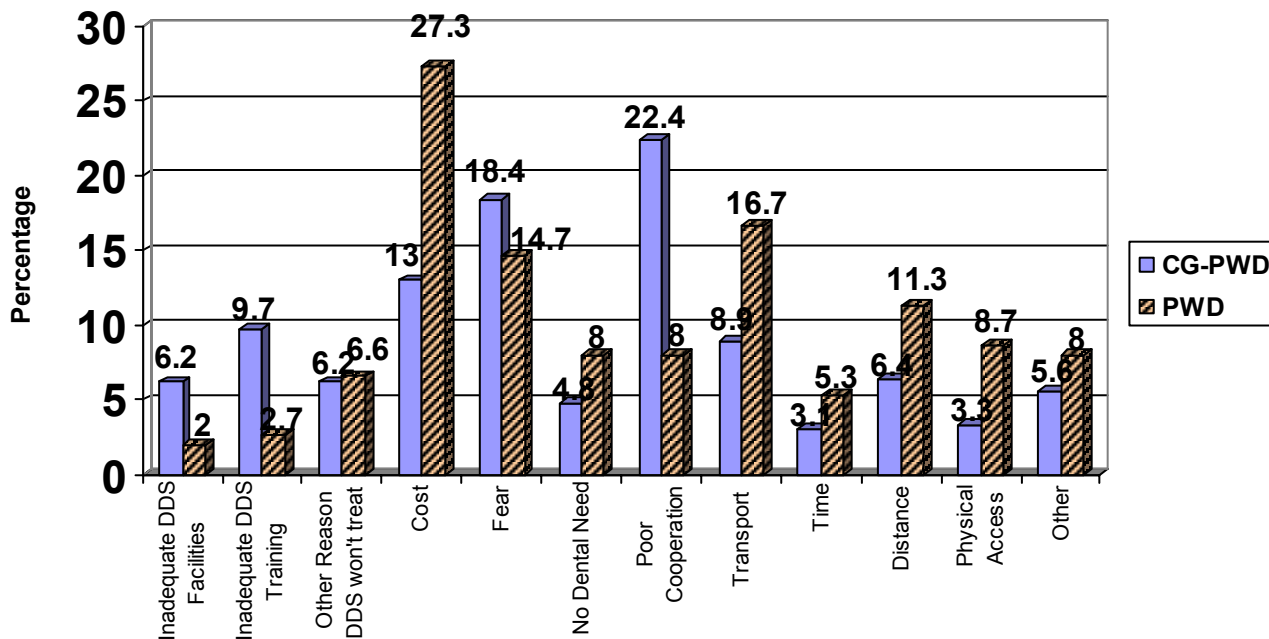


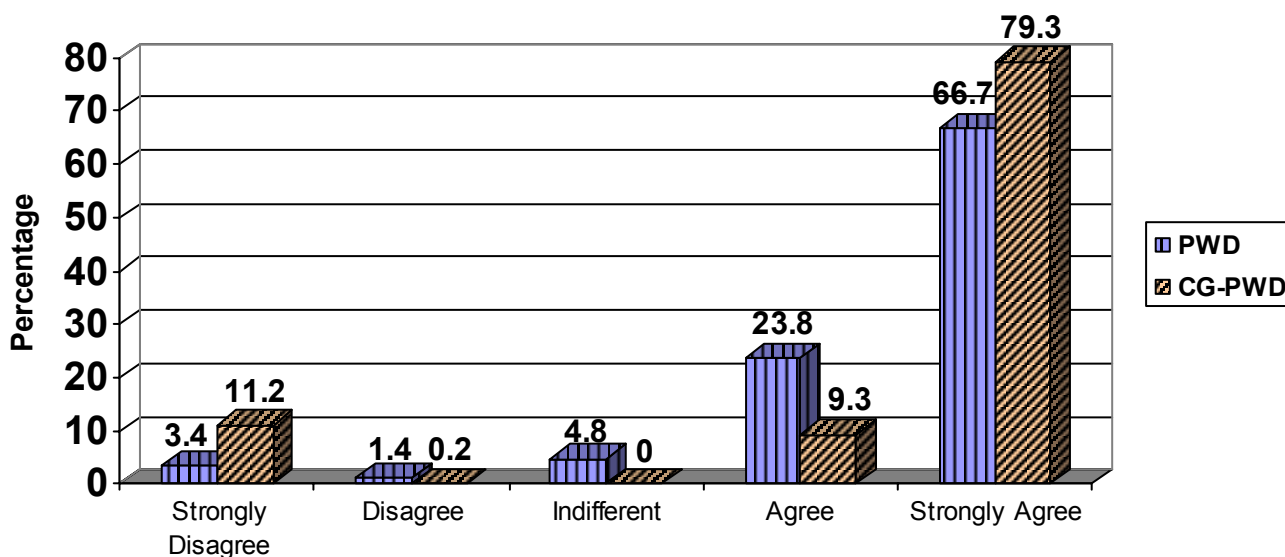
Figure 15. Most persons with disabilities do not require special modifications to receive dental treatment.

**Figure 16: Barriers to Accessing Dental Care**



**Figure 16.** Most persons with disabilities report dental fear, inability to cooperate with dental treatment, cost and transportation difficulties as barriers to accessing dental care.

**Figure 17: Oral Health Important For Overall Health**



**Figure 17.** The majority of persons with disabilities and caregivers for persons with disabilities believe that oral health is a component of overall health.

## DISCUSSION

The majority (73.2%) of persons with disabilities in the present study were able to access dental care in Ontario (based on pooled data from both the CG-PWD and PWD groups) with 87.4% of the CG-PWD group and 77.3% of the PWD group visiting the dentist within the past year. These rates are better than the general rate of 70% reported for all Ontarians in 2003 (Millar, 2004), and are similar to other studies looking at dental service utilization by persons with disabilities: 66% (Cumella, Ransford, Lyons, & Burnham, 2000); 74.3% (McDermott & El-Badrawy, 1986); 95% (Burtner et al., 1990); 82% (Manley & Pahl, 1989); 90% (Kaye et al., 2005). These findings although encouraging cannot disprove the study's original hypothesis that persons with disabilities in Ontario encounter difficulty accessing dental care. The reason is that the distribution of persons with disabilities sampled in this study is not representative of persons with disabilities in Ontario (persons with developmental disabilities were overrepresented) and 26% of persons with disabilities in this study reported difficulty accessing dental care. The problem with claiming 'good' access to dental care is that a current definition does not exist for what numerically represents 'good' access. If the medical model with a utilization rate of 94%, is deemed to represent 'ideal' access, access to dental care by this standard is poor in Ontario regardless of disability status. The only accurate statement that can be made from this study is that the majority of persons with developmental disabilities are able to access dental services in Ontario.

Internal patient factors were associated with greater difficulty accessing dental care than external factors. These internal factors were an inability to cooperate with dental treatment (18.9%), dental fear (17.5%) and a perception of a lack of dental problems (5.5%), whereas external barriers to accessing dental care were issues related to cost (16.4%), transportation difficulties (10.7%), adequacy of dentist training (8%), dental clinic proximity (7.6%), adequacy of dental facilities (5.2%), physical accessibility of dental clinics (4.6%) and a lack of time to see the dentist (3.6%). Internal patient factors such as having dental anxiety, being unable to cooperate with dental treatment, or being unable to communicate dental pain can affect a person's ability to access dental care as these factors can lead to avoidance behaviours such as canceling or missing dental appointments. Dental anxiety of varying levels currently affects 15% of Canadians (Changpong, Haas & Locker, 2005). Changpong, Haas and Locker (2005) reported that 42-54% of Canadians demonstrated an interest in sedation or general anesthesia to alleviate dental anxiety during dental treatment. Similar interests were found in the present study with 45% of persons with disabilities needing sedation (23%) or general anesthesia (22%). Persons with disabilities who needed these modifications were more likely to have greater difficulty accessing dental care than 51% who did not need special modifications. These findings are similar to other studies (Finger & Jedrychowksi, 1989; Russell & Kinirons, 1993; Steifel, 1981; Tesini & Fenton, 1994).

In addition to sedation and general anesthesia, other modifications needed to receive dental treatment were wheel chair transfer, use of protective support,

antibiotic prophylaxis, presence of caregivers in treatment room and dentist interaction to reduce anxiety. Persons with disabilities who needed only non-pharmacological modifications had less difficulty accessing dental care than those who required sedation. Most dental clinics are now wheel chair friendly and dental treatment can be provided to patients while they are seated in wheel chairs and depending on a patient's weight, most wheel chair transfers can be made with the help of caregivers. In terms of the need for protective support, not all patients with maladaptive behaviours are candidates for sedation and general anesthesia, and so the use of protective support, however controversial, remains a viable option for treating these patients. In addition to behaviour management methods, dentist factors were also found to be an important 'modification' for successful dental treatment. Caregivers from previous studies reported similar findings, identifying dentist qualities such as friendliness, patience, knowledge of disabling condition, gentleness, and direct communication as being desirable (Grant, Carlson, & Cullen-Erickson, 2004; Kaye et al., 2005; McDermott & El-Badrawy, 1986). Such dentist qualities, while beneficial for treating persons with disabilities, are not unique; all patients, regardless of disability status, can benefit from a friendly, patient, knowledgeable dentist.

While in most cases, type of disability was not found to be a major factor in determining access to dental care, a diagnosis of autism spectrum disorder (ASD) in the self-reporting PWD group was related to greater difficulty accessing dental care than in the CG-PWD group. This could be a reflection of an inability of these respondents in the PWD group to tolerate dental treatment without special

modifications. The spectrum of autistic disorders is broad and there maybe other contributing factors such as dental anxiety and aversions that can make receiving dental treatment difficult for this population. Persons with ASD who live independently may also have difficulty navigating community resources to find dental services that meet their needs.

Aside from dental anxiety, another internal barrier to dental care found in 4.8% of the CG-PWD group and 8% of the PWD group was the belief that the person with a disability had nothing wrong with his/her teeth and therefore did not need to see a dentist. This lack of perceived dental need in persons with disabilities was also found in other studies (Al Agili et al., 2004; Grant et al., 2004; Lo et al., 1991; Pezzementi & Fisher, 2005). Social and medical issues are often given greater priority than oral health issues and oral health only becomes a concern when symptoms arise such as pain. In the present study a person with a disability, with an inability to communicate dental pain as reported by the CG-PWD group, was more likely to experience difficulty accessing dental care. The difficulty for this population may be due to the fact that some persons with an inability to communicate dental pain may also have an inability to understand and cooperate for dental treatment and therefore require some type of special modification. As mentioned before, the need for special modifications to receive dental treatment was associated with greater difficulty accessing dental care. Caregivers who are unaware that their charges are in pain, or who do not perceive their charges to have dental needs, render their charges more susceptible to dental neglect. Dental apathy and ignorance can significantly affect oral health if preventable

dental disease is left untreated. Beliefs of persons with disabilities and their caregivers can thus affect whether they seek dental care, but these belief systems can affect persons without disabilities in the same manner. So while individual characteristics of persons with disabilities appear to be the limiting factor in accessing dental care, similar internal qualities applicable to all persons would lead to similar results. That is to say, a person's difficulty accessing dental care is not specific to the presence of a disability.

The finding that 26.3% of persons with disabilities had difficulty obtaining dental care in Ontario (based on pooled data from the CG-PWD and PWD groups) is similar to values reported in other studies: 14.8% in Iowa, 27.1% in France, and 40% in Florida (Allison et al., 2000; Burtner et al., 1990; McGrady et al., 2001). The authors in the France study commented that this rate may be lower than the true value, due to the fact that the sample may have been more motivated and aggressive in seeking dental care and therefore more successful in obtaining care (Allison et al., 2000). The present study may have reflected a similar bias as data was not available from the non-responders in terms of their ability to access dental care. In the Florida study despite 73% of their charges being cooperative for dental treatment, 40% of group home operators reported difficulty locating a dentist and only 33% of their charges received comprehensive dental services. Reasons cited for difficulty locating a dentist were external barriers such as refusal to accept persons with disabilities due to poor remuneration, dentist not being trained, office not being equipped or dentist being too busy (Burtner et al., 1990).

Dentist refusal to treat persons with disabilities has been mentioned in many studies (Al Agili et al., 2004; Allison et al., 2000; Finger & Jedrychowksi, 1989; Persson et al., 2000; Steifel, 1981). In the present study dentist refusal was not found to be a significant reason affecting access to dental care. In Ontario Leoppky & Sigal, 2006 found that 89% of general dentists reported treating persons with disabilities. In the present study less than 10% of both the CG-PWD and PWD groups reported that a dentist was unwilling to treat them. This refusal was due to similar reasons as in the Florida study (Burtner et al., 1990), such as inadequate training, inadequate facilities, and refusal to accept government programs such as the Ontario Disability Support Program (ODSP). The complaint of inadequate dentist training and inadequate facilities was reported by more of the CG-PWD group than the PWD group and may be related to the fact that more persons with disabilities in the CG-PWD group had severe developmental disabilities, possibly requiring the use of special modifications. In 1993, dental programs devoted 12.9 hours of didactic teaching and 17.5 hours of clinical training to their dental students in the care of persons with disabilities (S. J. Fenton, 1993). In 1999 dentist training was reduced to 5 hours of didactic teaching and to less than 10 hours of clinical training (Romer, Dougherty, & Amores-Lafleur, 1999) and as of 2004, only 25% of general dentists reported they had treated persons with disabilities when they were dental students (Casamassimo, Seale, & Ruehs, 2004). It is unknown whether changes to dentist training have impacted the present study's findings. The few persons with disabilities or caregivers who complained about inadequate dentist training could have been referring to the fact that some general dentists were not

trained to or chose not to provide sedation or general anesthesia services. This preference by the dentist or the lack of training would have affected all patients who wanted sedation regardless of disability status. The complaint of inadequate dentist facilities also appeared to refer to a lack of sedation equipment or general anesthesia capability based on open-ended responses. By far, the most common complaint as to why dentists refused to treat persons with disabilities was the lack of acceptance of remuneration by the Ontario Disability Support Program (ODSP). The purpose of government programs like ODSP is to enhance access to care, but instead, some dentists choose not to accept ODSP 's payment scale because it will not cover their overhead expenses (Farrell, 2001; Shosenberg, 2001). Persons with disabilities who had both private dental insurance and ODSP coverage reported the best access to dental care. Persons with disabilities in the CG-PWD group who only had private dental insurance or only government coverage reported greater difficulty accessing dental care than those people without coverage or with combinations of coverage. While this finding may seem counterintuitive, it could be explained by the fact that most dentists do not bill insurance companies directly, instead requiring their patients to pay up-front for their dental treatment. So even if a person with a disability has private dental insurance, if they cannot pay up-front, they may still have difficulty obtaining dental care. Also, the fact that some caregivers for persons with disabilities are affluent may explain why some persons with disabilities without dental insurance in the CG-PWD group had better access than those with coverage. Contrary to the CG-PWD group, self-reporting persons with disabilities (PWD group) were less likely to

have private insurance or ODSP and were more likely to report difficulty accessing dental care. In Ontario, people with disabilities have lower incomes than their non-disabled peers and so if this low income is compounded by a lack of dental insurance, dental care may be unaffordable. For the general population in Canada, the possession of dental insurance and higher incomes equates to greater dental utilization (Millar, 2004). Cost was reported to be a barrier by 13% of the CG-PWD group and 27.3% of the PWD group. The fact that a greater number of the PWD group reported cost as a barrier could relate to the fact that fewer persons with disabilities in the PWD group had private dental insurance or government dental coverage.

Aside from cost, transportation difficulties were another external barrier cited by 8.9% of the CG-PWD group and 16.7% of the PWD group. This finding may be due to the fact that most persons with disabilities in the CG-PWD group had parents as caregivers who could drive them to appointments or formal caregivers in group homes who had organized means of transportation. On the other hand, persons with disabilities in the PWD group lived more independently and were often left to their own devices to coordinate transportation. Transportation problems can exist for both long and short distances to the dentist (Finger & Jedrychowksi, 1989; Persson et al., 2000; Pezzementi & Fisher, 2005). In Ontario private and public transportation programs provide transportation for people with disabilities. These programs offer accessible buses and contracted accessible vehicles such as taxi mini-vans. Examples of such programs are Wheel Trans, Wheelchair Accessible Transit Inc, and Toronto Para Transit in Toronto,

Transhelp in Peel, and Care-a-Van in Oakville. Other regions have similar municipal transportation services. Longer trip transportation is provided by private taxi, Greyhound, private ambulance or in some cases the Canadian Red Cross. Eligibility must be established for the use of para-transit services and eligibility criteria have been made stricter and narrower each year as funding is reduced.. Some disability transportation services charge a fee, require reservations and only travel at certain times. In cases of persons with disabilities who do not have access to private vehicles, transportation to and from dental appointments can take a half-day or longer. The extra time spent in transit equates to time lost working, further compounding financial difficulties in obtaining dental care (Al Agili et al., 2004; Pezzementi & Fisher, 2005).

Distance does affect access to dental care. The majority of persons with disabilities in the present study lived within 10 km from a dentist, most in an urban area such as metropolitan Toronto. McGrady et al., 2001 observed their respondents traveled a mean distance of 8.8 miles to a dentist and the average distance traveled to receive dental treatment in an operating room setting was 74.2 miles. Rural residents are less likely to visit a dentist than urban residents (Millar, 2004) and are more likely to have poorer health and confront more barriers in accessing care such as limited numbers of health care providers, absence of sophisticated services, lack of public transportation, and poverty (Iezzoni, Killeen, & O'Day, 2006). Some of the respondents in the present study reported visiting many dentists before finding a dentist who would accept them or in the case of

caregivers, their charges, as patients. In an urban area with greater dentist density, the odds of finding a dentist nearby who will treat are better than in rural settings.

Data for the present study were collected using a questionnaire. The questionnaire was in the English language and it is possible the vocabulary chosen did not accommodate all literacy levels. The questionnaire was also not available in large font or audio format. These shortcomings may have discouraged certain persons from participating in the study. In general, the recruitment of persons with disabilities for the study was difficult. The existence and availability of a comprehensive list of persons with disabilities in Ontario could not be determined. As a result, community organizations providing support to persons with disabilities were recruited to participate. These organizations were identified from online and phone directories and were asked to circulate the questionnaire to their members. All organizations identified which provided services for persons with developmental disabilities were placed on the list. Unfortunately some organizations may have been overlooked if they were not listed in the searched directories, resulting in sample bias. Institutions, rehabilitation centres, and elder care homes were not included. This additional sampling bias would explain why the distribution of persons with disabilities in this study were mostly persons with developmental disabilities, not persons with mobility or agility disabilities. From the 121 organizations that were asked to participate, 22 agreed. Membership information specific to the non-participating organizations could not be verified. It is possible that these organizations were interested in participating, but that they did not receive email and phone messages because their contact information was

outdated. Some organizations requested their own internal scientific review prior to circulating the questionnaire and in some cases their participation was lost through an inability to navigate through a network of contacts to complete the reviews. A few organizations were overwhelmed with their own agendas and could not cooperate within the time frame of the study's data collection. Another source of sampling bias was the assumption that the majority of persons with disabilities sought community services and were known to community organizations. It is possible that some persons with disabilities were completely marginalized and did not access support services, in which case, these people were inadvertently excluded from the study. Bureaucratic barriers, organization affiliations and our lack of knowledge of certain organizations ultimately influenced who formed the study's sampling frame. Other studies that sought participation of persons with disabilities reported similar difficulties in addition to other problems such as issues about informed consent, privacy and a lack of experience on the part of persons with disabilities in participating in research processes or understanding the need for research (Becker, Roberts, Morrison, & Silver, 2004).

Another area of concern regarding the use of a questionnaire instrument was the issues surrounding recall bias. Questionnaire respondents may not have understood the questions and therefore answered erroneously. In addition, the surveys were completed mostly by caregivers on behalf of a person with a disability. The caregivers may have answered according to their own beliefs and also may have answered in a way that portrayed them as being good caregivers, such as taking their charges for regular dental check-ups. One study observed that

depressed caregivers reported that their charges had more unmet health needs than non-depressed caregivers (Gaskin & Mitchell, 2005). It is clear that point of reference of the respondents affect their responses. This is very true for the perception of barriers. Some people with significant impairments do not consider themselves disabled, whereas others with minor impairments believe they have considerable limitations (Becker et al., 2004). Some people who live 100 km from a dentist may not consider that a far distance to travel for care whereas another person might feel 5 km is too far. To account for these opinions the present study attempted to gather data both objectively (5 km) by closed questions and subjectively (too far) by open ended questions.

The sample focus was persons with intellectual and developmental disabilities. Respondents who reported other types of disabilities were not excluded from the sample. The elderly however, who form a large proportion of persons with disabilities, were not represented. As mentioned before the overrepresentation of persons with developmental disabilities and underrepresentation of persons with agility or mobility disabilities was due to sampling bias. The final sample size was 634. Based on a population of 1.5 million persons with disabilities in Ontario, a sample of 384 was necessary for a power of 80%. The online questionnaire response rate was unknown, but the paper questionnaire response rate was 23.9%. While this low response rate introduced non-sampling bias into the present study and the findings cannot be generalized to rest of Ontario's population, the rate is similar to other studies: 21% (Al Agili et al., 2004); 31.2% (McDermott & El-Badrawy, 1986); 58.3% (Allison et al., 2000); 63.5% (Kaye

et al., 2005). Attempts to improve the response rate were not practical for this study because the investigators had to rely upon community organizations to mail out questionnaires. Many of the community organizations had limited resources and man-power to circulate even the initial mail-out. As it was unknown to whom the organizations sent the questionnaires, information about the non-responders could not be established. Non-sampling error is a major drawback to questionnaire-based methods. Strayer, Kuthy, & Sutton, 1993 compared differences between initial mail responders and non-responders followed-up by telephone and found no major differences in demographics. They did observe however, that perceptions about dental health and dentition status were different. It is possible that non-responders in the present study followed a similar pattern, having similar demographic characteristics as those who responded, but apathy towards oral health issues, leading them to not complete the questionnaire.

An electronic or internet based format of the questionnaire was used in addition to the paper format to increase responses. The web format was efficient and relatively inexpensive compared to the paper version (Ministry of Health Ontario, 2004). The problem encountered with the web questionnaire was that a denominator for a response rate calculation could not be established due to the fact that the questionnaire was accessible from websites, not from private emails sent to prospective participants. It is also possible that some people who received the paper format of the questionnaire, chose instead to complete the questionnaire online. Comparing the paper and web respondents revealed that the web respondents were more likely to be persons with disabilities who were older in age

(age 25-55), lived in central Ontario or metropolitan Toronto and lived independently. These differences may have reflected that the self-reporting persons with disabilities had less intellectual disability than the persons with disabilities in the CG-PWD group. The online respondents also may have had better access to computers and were more computer savvy than the caregivers in the CG-PWD group. Differences in access to computers and computer literacy could have been an additional source of sampling error in the present study (Dillman, 2000; Ministry of Health Ontario, 2004).

Most of the questionnaires were completed by caregivers on behalf of a person with a disability. Most of the caregivers were parents or guardians with their charges living with them in the family home. This is pattern is common for most persons with developmental disabilities in Ontario (*Opportunities and action: Transforming supports in Ontario for people who have a developmental disability*. 2006). As expected, the persons with disabilities who had the surveys completed by caregivers were younger or had more severe intellectual disability than the self-reporting persons with disabilities. Also expected was that most of the caregivers were females (Navaie-Waliser, Spriggs, & Feldman, 2002). Even in the PWD group, females completed more questionnaires than males. This may reflect greater concern by females for their oral health, supported by the fact that they are more likely to seek dental care than males (Millar, 2004). Geographically, most of the respondents were from the metropolitan Toronto area, and while this may be a function of sampling error, it may also be due to the geographic distribution of people in Ontario. The population density of southern Ontario is significantly

greater than northern Ontario. It is possible, that persons with disabilities and their families choose to live closer to the support services and health care facilities that are available in southern Ontario. In northern Ontario, regardless of ability status, Ontarians face reduced access to dental care because of fewer dentists (Mendel, 1997).

The results from the present study showed that the majority of people with disabilities had dental needs which required dental treatment (77.5% of the CG-PWD group and 65% of the PWD group). This observation however, could be interpreted in two ways: firstly, that these were unmet dental needs or secondly that these were needs in the process of being treated. The only valid interpretation of this observation is that most persons with disabilities and their caregivers identified a dental need being present. The fact that more than three quarters of persons with disabilities saw the dentist within the past year would suggest that dental needs were planned to be treated or in the process of being treated. Similarly, it could be assumed the persons who did not see a dentist on a regular basis were more likely to have unmet dental needs. In a different scenario, unmet dental needs could have been reported by persons who had seen a dentist, but felt that their treatment was inadequate. Undoubtedly, further clarification is needed before meaningful interpretation of this finding can be made, but unfortunately, follow-up questioning was not conducted.

The majority of persons with disabilities sought dental treatment from general dentists with only 30% needing to see a dental specialist. This finding is common in recent studies as persons with disabilities use the same dentist as the

rest of their families (Kaye et al., 2005). In Britain, the trend is moving away from the use of community dental services by persons with disabilities to greater utilization of the private dental sector (Cumella et al., 2000). Only a minority of persons with disabilities in the present study, as in other studies, required dental treatment in-hospital or required general anesthesia (Manley & Pahl, 1989; Russell & Kinirons, 1993).

The literature examining the oral health status of people with disabilities suggests that persons with disabilities suffer worse oral health than non-disabled people (Allison et al., 2000; Nunn, 1987; Pezzementi & Fisher, 2005). Historically institutionalized persons with disabilities had low caries rates but high prevalence of periodontal disease than non-institutionalized persons (Gabre & Gahnberg, 1997). This finding related to the fact that diet was more controlled in institutions, but oral hygiene practices were often neglected (Gabre, Martinsson, & Gahnberg, 2002). Persons with disabilities who now live in the community have less restrictive diets, leading to similar caries rates as the general population (Brown, 1980; Nunn, 1987). While it may be thought that regular attendance to the dentist would equate to good oral health, the truth is that many persons with disabilities have more untreated decay and more missing teeth compared with the general population (Crall, 2007; Hennequin et al., 2000; Nunn, 1987; Tiller et al., 2001; Wilson, 1992). Despite the possibility of unmet oral health needs however, the majority of caregivers in previous studies have been satisfied with the dental care their charges had received (Kaye et al., 2005; McDermott & El-Badrawy, 1986). Unmet oral health needs may be a function of an inability of the dentist to obtain an

accurate diagnosis due to certain patient factors as mentioned before (Hennequin et al., 2000). Nearly half (47.1%) of the CG-PWD group had difficulty communicating dental pain, while 12.3% of the persons with disabilities self-reported similar difficulty. An inability to communicate can lead to underestimation of dental need, but also to difficulty formulating treatment plans that incorporate patient values. In this regard, treatment planning for many persons with disabilities takes on a paternalistic role.

Although the present study's primary focus was not related to quality of dental care, dental experiences of persons with disabilities in Ontario were explored in terms of appointment time and types of dental treatment. The majority of persons with disabilities experienced a waiting room time of less than 30 minutes in private settings, similar to findings by Al Agili et al., 2004, where 50% of respondents claimed always waiting more than 15 minutes. In the present study, persons with disabilities who attended hospital dental clinics faced even longer waiting room times, sometimes waiting as long as one to two hours. Studies show that short waiting room times less than 30 minutes are consistent with greater patient satisfaction (Anderson, Camacho & Balkrishnan, 2007). In regards to appointment duration, 62.7% of persons with disabilities spent up to 1 hour total combined time with a dental hygienist and dentist. One hour appears to be the average time required for dental examination and prophylaxis for the general population (U.S. Army Center for Health Promotion and Preventive Medicine, 2007). In terms of dentist time, 30 minutes appears to be in keeping with the average appointment length reported for dental specialists of 30 minutes or less

and 40-60 minutes for general dentists (Survey of dental practice VIII. number of patients and patient visits: Usual length of patient appointments. reports of councils and bureaus. 1972). Therefore it appears that the time spent by persons with disabilities at the dental office is similar to that of the general population.

Nearly all persons with disabilities in the present study had a dental examination and prophylaxis, but were more likely to have extractions and fillings compared to procedures such as sealants or major restorative treatment such as crown and bridge, endodontic therapy or orthodontic treatment. This finding is similar to other studies (Chohayeb, 1985; Kaye et al., 2005; Pezzementi & Fisher, 2005). Some of the open-ended responses by a few caregivers displayed frustration, stating that dentists preferred to extract rather than preserve teeth and that dentists were unwilling to fabricate dentures or provide orthodontic treatment for their charges. Dentists' beliefs do affect treatment planning for their patients, but for the most part in a beneficial manner. Just as not all health professionals are the right match for an individual, not all dentists are right for everyone. Persons with disabilities and their caregivers, just as anyone else, need to find dentists who match their values. In certain situations however, some dental treatments are contraindicated because of unfavorable patient factors (poor oral hygiene, poor health status).

It appears that persons with disabilities face few additional barriers to obtaining dental care as the general population. Dentist refusal to treat because of inadequate training or facilities is still a potential barrier faced by persons with disabilities. Reliance on third parties such as caregivers and primary care

providers to coordinate dental treatment is problematic because of conflicts of values, attitudes, consent and schedules. While most persons with disabilities do not require special modifications and receive dental care from their communities, in some cases persons with severe developmental and physical disabilities may require general anesthesia to receive dental treatment. Needing general anesthesia for routine dental treatment limits the delivery of care to a few providers. This means traveling greater distances for care and waiting a long time to receive care. Persons in the general population with dental anxiety and fear face similar difficulties accessing publicly funded general anesthesia services. Environmental barriers to obtaining dental care such as stairs or small dental operatories are still a reality. Many persons with disabilities need assistance with transportation, and help with attending appointments. The general population may not encounter similar physical barriers. Another difference between the general population and persons with disabilities in Ontario is that most persons with disabilities are in receipt of the Ontario Disability Support program. This program covers routine dental treatment. Low income adults in Ontario, despite receiving Ontario Works, could only until recently obtain emergency dental services. Outside of financial, environmental and attitudinal barriers, other issues such as shortage of dentists in rural areas, cultural and language issues, remain the same (Reichard et al, 2004).

Utilization of dental services as observed is similar to the general population, but appears to lag behind utilization of medical services. To improve dental utilization amongst persons with disabilities, reimbursement rates for the

Ontario Disability Support program must be increased, access to general anesthesia services should be improved, dental care coordination should occur with medical care, regular family dentists should be identified and education of persons with disabilities and caregivers about the importance of dental care should be promoted. Dentists should be familiar with how to coordinate dental care efficiently for patients with disabilities, and a list of dentists who have experience treating persons with disabilities and who are accepting new patients should be established and distributed to persons with disabilities and caregivers. Other measures to reduce language barriers, cultural barriers, and increase dental personnel in underserved areas would also contribute to improve dental utilization.

#### ORAL HEALTH AS AN IMPORTANT COMPONENT OF OVERALL HEALTH

The majority of caregivers and persons with disabilities believe that oral health is an important part of overall health. This finding supports the study's second hypothesis and is supported by similar findings in other studies (McDermott & El-Badrawy, 1986; Persson et al., 2000). Persson et al., 2000 observed that persons with disabilities were more likely to report oral health having an effect on their general health than those without disabilities. The belief system of caregivers is important in determining whether caregivers seek dental care for their charges. Studies have shown that informal caregivers with poor oral health have charges whom are more susceptible to dental neglect (Grant et al., 2004; Kaye et al., 2005). In the case of group homes, dental examinations are mandated for annual licensure. In these situations, formal caregivers must take their charges

to the dentist. It is possible that despite mandated dental examinations and treatment, persons with disabilities in group home settings suffer poor oral health as result of inadequate oral hygiene measures. In the present study, no relationship was found between caregiver opinion or the opinion of persons with disabilities and access to dental care or dental visit frequency. For the minority who believed oral health was not integral to general health, this belief did not seem to prevent them from visiting the dentist. This may have reflected a need for emergency dental treatment or another belief system that necessitated dental utilization.

## SUMMARY

Access to dental care is a function of the availability of dental care and a person's desire to seek care. In Ontario, the medical safety net is far greater than the dental safety net. Dental services are maldistributed throughout Ontario and further limiting factors such as financial and bureaucratic barriers reduce a person's ability to obtain dental care. Despite these inadequacies however, 73.2% of persons with disabilities, primarily developmental disabilities, were able to access dental services in Ontario. The fact that individual characteristics and attitudes of persons with disabilities affected access to dental care more than external contextual factors implies that difficulty accessing dental care by persons with disabilities in Ontario is not related to an inability of Ontario's dental community to provide dental treatment. Most persons with disabilities in Ontario have a regular dentist, and report no need for special modifications to receive

dental care. Those who do require special modifications however, as result of dental anxiety or an inability to cooperate while awake for dental treatment, experience the greatest difficulty. Nearly all the caregivers (88.6%) and persons with disabilities (90.7%) in the present study valued oral health. Factors other than the belief that 'oral health is important for overall health' seem to affect dental attendance because even those who believed differently saw the dentist on a regular basis.

## FUTURE STUDIES

Future studies should investigate ways to improve dental experiences and access to dental care for the dentally anxious, apathetic and dentally marginalized. New studies should also attempt to utilize protocols that improve respondent participation and collection of data such as income and education levels. Another area requiring further research is patient satisfaction and the quality of dental services for persons with disabilities. These areas should be explored in terms of clinical determinants of quality of dental treatment, oral health status and the timeliness, efficiency, and effectiveness of available dental services.

## BIBLIOGRAPHY

- Advisory Committee on Population Health (ACPH). (2000). *Toward a healthy future. Second report on the health of Canadians 1999*. No. 2. Ottawa: Health Canada.
- Al Agili, D. E., Roseman, J., Pass, M. A., Thornton, J. B., & Chavers, L. S. (2004). Access to dental care in Alabama for children with special needs: Parents' perspectives. *Journal of the American Dental Association*, 135(4), 490.
- Allison, P. J., Hennequin, M., & Faulks, D. (2000). Dental care access among individuals with Down syndrome in France. *Special Care Dentist*, 20(1), 28.
- Allison, P.J., Lawrence, H.P. (2004). A paired comparison of dental care in Canadians with Down syndrome and their siblings without Down syndrome. *Community Dentistry and Oral Epidemiology*, 32, 99-106
- Anderson, R.T., Camacho, F.T., & Balkrishnan, R. (2007). Willing to wait? The influence of patient wait time on satisfaction with primary care. *BMC Health Services Research*, 7, 31.
- Anglin, B., & Braaten, J. (1978). *Twenty-five years of growing together. A history of the Ontario association for the mentally retarded*. Canadian Association for the Mentally Retarded.
- Baird, A., & Abate, R. (2000). Hospital restructuring, downsizing and cutbacks- the impact on hospital-based dentistry. *Ontario Dentist*, 23.
- Balogh, R. S., Oullette-Kuntz, H., & Hunter, D. J. W. (2004). Regional variation in dental procedures among people with an intellectual disability, Ontario 1995-2001. *Journal of the Canadian Dental Association*, 70(10), 681.
- Becker, H., Roberts, G., Morrison, J., & Silver, J. (2004). Recruiting people with disabilities as research participants: Challenges and strategies to address them. *Mental Retardation*, 42(6), 471-475.
- Benzie, R. (2007, November 29). Poor to get dental plan. *The Toronto Star*. Retrieved January 20, 2008, from <http://www.thestar.com/News/Ontario/article/280928>.
- Bourke, L. F., & Jago, J. D. (1983). Problems of persons with cerebral palsy in obtaining dental care. *Australian Dental Journal*, 29, 221.
- Braff, M. H. (1985). Dental treatment for developmentally disabled patients. *Special Care Dentist*, 5(3), 109.

- Brown, J. P. (1980). The efficacy and economy of comprehensive dental care for handicapped children. *International Dental Journal*, 30, 16.
- Burtner, A.P., Dicks, J.L. (1994). Providing oral health care to individuals with severe disabilities residing in the community: alternative care delivery systems. *Special Care in Dentistry*, 14 (5), 188-193.
- Burtner, A. P., Jones, J. S., McNeal, D. R., & Low, D. W. (1990). A survey of the availability of dental services to developmentally disabled persons residing in the community. *Special Care Dentist*, 10, 182.
- Canadian Dental Association. (2005a). *Dentist-to-population ratios by province (1995-2005)*. Retrieved June 22, 2007, from [http://www.cda-adc.ca/en/members/resource/fact\\_sheets/](http://www.cda-adc.ca/en/members/resource/fact_sheets/)
- Canadian Dental Association. (2005b). *Highlights dental care expenditures in Canada in 2005*. Retrieved June 22, 2007, from [http://www.cda-adc.ca/en/members/resource/fact\\_sheets/dental\\_expenditures.asp](http://www.cda-adc.ca/en/members/resource/fact_sheets/dental_expenditures.asp)
- Canadian Dental Association. (2005c). *Percent of population having consulted dental professional in the past 12 months by province/territory (1994-2003)*. Retrieved June 22, 2007, from <http://www.cda-adc.ca/>
- Casamassimo, P. S., Seale, N. S., & Ruehs, K. (2004). General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. *Journal Dental Education*, 68(1), 23.
- Chalmers, J. M., Kingsford-Smith, D., & Carter, K. D. (1998). A multidisciplinary dental program for community-living adults with chronic mental illness. *Special Care Dentist*, 18(5), 194.
- Chanpong, B., Haas, D. A., & Locker, D. (2005). Need and demand for sedation or general anesthetic in dentistry: a national survey of the Canadian population. *Anesthesia Progress*, 52 (1), 3.
- Chohayeb, A. A. (1985). Prevalent medical and dental conditions among the handicapped. *Special Care Dentist*, 5, 114.
- Citizenship and Immigration Canada. (2001). *Interim federal health program. information handbook for healthcare providers*. Retrieved June 22, 2007, from [http://www.fasadmin.com/images/pdf/ifh\\_information\\_handbook.pdf](http://www.fasadmin.com/images/pdf/ifh_information_handbook.pdf)
- Clark, C. A., & Vanek, E. P. (1984). Meeting the health care needs of people with limited access to care. *Journal Dental Education*, 48(4), 213.
- Crall, J. J. (2007). Improving oral health for individuals with special health care needs. *Pediatric dentistry*, 29(2), 98-104.

- Cumella, S., Ransford, N., Lyons, J., & Burnham, H. (2000). Needs for oral care among people with intellectual disability not in contact with community dental services. *Journal of Intellectual Disability Research*, 44(part 1), 45.
- DHHS. (2000). *Oral health in America: A report of the surgeon general*. Rockville, Md.: National Institute of Dental and Craniofacial Research, National Institutes of Health.
- Dillman, D. A. (2000). *Mail and internet surveys: The tailored design method*. (2nd ed.). New York: Wiley and Sons.
- Duhamel, R. (1963). *Report on the administration of allowances for disabled persons in Canada*. Canada: Department of National Health and Welfare.
- Edelstein, B. L. (2007). Conceptual frameworks for understanding system capacity in the care of people with special health care needs. *Pediatric dentistry*, 29(2), 108-116.
- EFA. (2007). *Dental and eyeglasses subsidies*. Retrieved June 22, 2007, from [http://www.ottawa.ca/residents/efa/living\\_costs/dental\\_eyeglasses\\_en.html](http://www.ottawa.ca/residents/efa/living_costs/dental_eyeglasses_en.html)
- Farrell, N. A. (2001). Twenty-five years of dental public health in Ontario. *Ontario Dentist*, 13.
- Fenton, S. J. (1993). 1993 survey of training in the treatment of persons with disabilities. *Interface.*, 9(7), 1.
- Fenton, S. J., Hood, H., Holder, M., May, P. B., Jr, & Mouradian, W. E. (2003). The American academy of developmental medicine and dentistry: Eliminating health disparities for individuals with mental retardation and other developmental disabilities. *Journal of Dental Education*, 67(12), 1337-1344.
- Finger, S. T., & Jedrychowksi, J. R. (1989). Parents' perception of access to dental care for children with handicapping conditions. *Special Care Dentist*, 9(6), 195.
- Gabre, P., & Gahnberg, L. (1997). Inter-relationship among degree of mental retardation, living arrangements, and dental health in adults with mental retardation. *Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry*, 17(1), 7-12.
- Gabre, P., Martinsson, T., & Gahnberg, L. (2002). Move of adults with intellectual disability from institutions to community-based living: Changes of food arrangements and oral health. *Swedish Dental Journal*, 26(2), 81-88.
- Gardner, D. G. (1972). *Task force on dental care for the mentally retarded*. Ontario: Ontario Ministry of Health.

- Gaskin, D. J., & Mitchell, J. M. (2005). Health status and access to care for children with special health care needs. *Journal Mental Health Policy and Economics.*, 8(1), 29.
- Glasgow, D. (2005). Accerta cuts its teeth in the private sector. *Ontario Dentist*, 33.
- Glassman, P. (2005) New models for improving oral health for people with special needs. *California Dental Journal*, 33(8), 625-633.
- Gordon, S. M., Dionne, R. A., & Snyder, J. (1998). Dental fear and anxiety as a barrier to accessing oral health care among patients with special health care needs. *Special Care Dentist*, 18, 88.
- Grant, E., Carlson, G., & Cullen-Erickson, M. (2004). Oral health for people with intellectual disability and high support needs: Positive outcomes. *Special Care Dentist*, 24(2), 70.
- Guay, A. H. (2004). Access to dental care: The triad of essential factors in access-to-care programs. *Journal of the American Dental Association*, 135(6), 779.
- Hargreaves, J. A., Levine, N., & Atkins, G. D. (1976). Canadian attitudes on delivery of dentistry for the handicapped. In P. Wetphal (Ed.), *Proceeding of the 3rd international congress on dentistry for the handicapped*. (pp. 22)
- Hennequin, M., Faulks, D., & Roux, D. (2000). Accuracy of estimation of dental treatment need in special care patients. *Journal of Dentistry*, 28(2), 131.
- Hodgins, F. E. (1919). *Report on the care and control of the mentally defective and feeble-minded in Ontario*. Toronto: A.T. Wilgress.
- HRSDC. (2006). *Advancing the inclusion of persons with disabilities*. Office for Disability Issues, Human Resources and Social Development Canada.
- Iezzoni, L.I., Davis, R.B., Soukop, J., & O'Day, B. (2002). Satisfaction with quality and access to health care among people with disabling conditions. *International Journal for Quality in Health Care*, 14(5), 369.
- Iezzoni, L. I., Killeen, M. B., & O'Day, B. L. (2006). Rural residents with disabilities confront substantial barriers to obtaining primary care. *Health Services Research*, 41(4), 1258.
- Johnson, I., Goettler, F., Goral, A., Leffley, A., & et al. (2000). *Report on the health status of the residents of Ontario*. PHRED Partners.
- Kamen, S. (1981). Dental management of patients with mental retardation and related developmental disorders. *Journal of the Canadian Dental Association*, 10, 653.

- Kasman, N.M., & Badley, E.M. (2004). Beyond access: who reports that health care is not being received when needed in a publicly-funded health care system? *Canadian Journal of Public Health*, 95(4), 304-308.
- Kenny, D.J., & McKim, J.S. (1971) Dental care demand for mongoloid and cerebral palsied children. *Journal of the Canadian Dental Association*, 37 (7), 270-4.
- Kaye, P. L., Fiske, J., Bower, E. J., Newton, J. T., & Fenlon, M. (2005). Views and experiences of parents and siblings of adults with Down syndrome regarding oral health care: A qualitative and quantitative study. *British Dental Journal*, 198(9), 571.
- Kucey, S. P. (1979). The dental practitioner and hospital affairs in Ontario. *Ontario Dentist*, 56(6), 27.
- Lawrence, H.P. Leake, J. L. (2001). The U.S. Surgeon General's report on oral health in America: A Canadian perspective. *Journal of the Canadian Dental Association*. 67(10), 587.
- Lawton, L. (2002). Providing dental care for special patients. tips for the general dentist. *Journal of the American Dental Association*, 133, 1666.
- Locker, D. (2001). Does dental care improve the oral health of older adults? *Community Dental Health*, 18(1), 7-15.
- Loeppky, W., Sigal, M. (2006). Patients with special health care needs in general and pediatric dental practices in Ontario. *Journal of the Canadian Dental Association*. 72(10), 915.
- Lo, G. K., Soh, G., Vignehsa, H., & Chellappah, N. K. (1991). Dental service utilization of disabled children. *Special Care Dentist*, 11(5), 194.
- Manley, M. C., & Pahl, J. M. (1989). Dental services for children with mental handicaps: Policy changes and parental choices. *British Dental Journal*, 167(5), 163.
- Matear, D., Barbaro, J. (2006). Caregiver perspectives in oral healthcare in an institutionalized elderly population without access to dental services: a pilot study. *The Journal of the Royal Society for the Promotion of Health*, 126 (1): 28-32.
- McDermott, R. E., & El-Badrawy, H. E. (1986). A survey of parents' perceptions of the dental needs of their handicapped child. *Journal of the Canadian Dental Association*, 52, 425.
- McGrady, J. A., Kanellis, M. J., Warren, J. J. & Levy, S. M. (2001). *Access to dental care for group home residents in Iowa*. Retrieved June 22, 2007, from

<http://www.healthychild.ucla.edu/nohpc/National%20Oral%20Health%20Policy%20Center/Publications/Promoting%20Oral%20Health.pdf>

- MCSS. (2006a). *ODSP*. Retrieved June 22, 2007, from <http://www.mcass.gov.on.ca/mcass/english/pillars/social/programs/odsp.htm>
- MCSS. (2006b). *Ontario works*. Retrieved June 22, 2007, from <http://www.mcass.gov.on.ca/mcass/english/pillars/social/programs/ow.htm>
- MCSS. (2006c). *Reshaping community-based specialized services in Ontario*. Retrieved June 22, 2007, from <http://www.mcass.gov.on.ca/mcass/english/news/backgrounders/060302.htm>
- MCSS. (2006d). *Residential supports*. Retrieved June 22, 2007, from [http://www.mcass.gov.on.ca/mcass/english/pillars/developmental/programs/resident\\_support.htm](http://www.mcass.gov.on.ca/mcass/english/pillars/developmental/programs/resident_support.htm)
- MCSS. (2007a). *Ontario disability statistics*. Retrieved June 22, 2007, from [http://www.mcass.gov.on.ca/mcass/english/topics/pop\\_ado\\_stats.htm](http://www.mcass.gov.on.ca/mcass/english/topics/pop_ado_stats.htm)
- MCSS. (2007b). *Transforming developmental services*. Retrieved June 22, 2007, from [http://www.mcass.gov.on.ca/mcass/english/pillars/developmental/what/why\\_transform\\_dev\\_services.htm](http://www.mcass.gov.on.ca/mcass/english/pillars/developmental/what/why_transform_dev_services.htm)
- MCSS News Release. (May 2, 2006). *McGuinty government makes historic commitment to stronger services for people with A developmental disability.*, 2007, from <http://www.mcass.gov.on.ca/mcass/english/news/releases/060502.htm>
- MCYS. (2007). *Assistance for children with severe disabilities*. Retrieved June 22, 2007, from <http://www.children.gov.on.ca/CS/en/programs/SpecialNeeds/assistanceforChildrenwithSevereDisabilities.htm>
- Mendel, J. (1997). Dental human resource distribution in Ontario: A report for 1997. *Ontario Dentist*, 36.
- Merry, E. J., & Edwards, D. M. (2002). Disability part 1: The disability discrimination act (1995) - implications for dentists. *British Dental Journal*, 193(4), 199.
- Millar, W. J. (2004). Dental consultations. *Statistics Canada Health Reports*, 16(1), 41.
- Ministry of Health Ontario. (2004). Use of a web-based survey as a data collection strategy in public health. *Public Health and Epidemiology Report Ontario*, 15(3), 104.

- MOHLTC. (2007). *The Ontario cleft lip and Palate/Craniofacial dental program*. Retrieved June 22, 2007, from <http://www.health.gov.on.ca/english/public/pub/child/cleft.html>
- Navaie-Waliser, M., Spriggs, A., & Feldman, P. H. (2002). Informal caregiving: Differential experiences by gender. *Medical care*, 40(12), 1249-1259.
- Non-insured health benefits program 2004-2005 annual report*. (2005). Retrieved June 22, 2007, from [http://www.hc-sc.gc.ca/fnih-spni/pubs/nihb-ssna/2005\\_rpt/index\\_e.html](http://www.hc-sc.gc.ca/fnih-spni/pubs/nihb-ssna/2005_rpt/index_e.html)
- Nunn, J. H. (1987). The dental health of mentally and physically handicapped children: A review of the literature. *Community Dental Health*, 4(2), 157-168.
- O'Donnell, D. (1985). Handicapped people in Hong Kong: The problems of access to dental care. *Journal Research Social Health.*, 195(4), 141.
- O'Donnell, J. P. (1994). Dental care for special needs individuals : A new barrier to access. *Special Care Dentist*, 14(5), 178.
- O'Donnell, D. (1996). The special needs patient. treatment in general dental practice: Is it feasible? *International Dental Journal*, 46(4), 315-319.
- Oliver, C.H. Nunn, J.H. (1996). The accessibility of dental treatment to adults with physical disabilities in northeast England. *Special Care Dentist*, 16(5), 204.
- Ontario health survey, 1990 : Highlights*.(1992). In Ontario. (Ed.), . [Toronto]: Ontario Ministry of Health.
- Ontario human rights code. R.S.O. 1990.c.H.19*. (2006). Retrieved June 22, 2007, from [http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/90h19\\_e.htm](http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/90h19_e.htm)
- OPHA. (2005). Position statement on poverty and children's oral health. Retrieved December 15,2007, from [http://www.opha.on.ca/ppres/2005-02\\_pp.pdf](http://www.opha.on.ca/ppres/2005-02_pp.pdf)
- Opportunities and action: Transforming supports in Ontario for people who have a developmental disability*. (2006). Retrieved June 22, 2007, from <http://www.mcass.gov.on.ca/NR/rdonlyres/D643669A-74A8-420C-8042-6D46343106C1/92DSreport.pdf>
- Overview of the task force report* (1980). Ministry of Community and Social Services.
- Perenboom, R. J., & Chorus, A. M. (2003). Measuring participation according to the international classification of functioning, disability and health (ICF). *Disability Rehabilitation*, 25(11-12), 577.

- Persson, R. E., Stiefel, D. J., Griffith, M. V., Truelove, E. L., & Martin, M. D. (2000). Characteristics of dental emergency clinic patients with and without disabilities. *Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry*, 20(3), 114-120.
- Pezzementi, M. L., & Fisher, M. A. (2005). Oral health status of people with intellectual disabilities in the southeastern United States. *Journal of the American Dental Association* (1939), 136(7), 903-912.
- Pratt, L. (1997). The face of dentistry in Ontario. A comparison of rural and urban dentists' lifestyles. *Ontario Dentist*, 74(5), 40-43.
- Reichard, A., Sacco, T.M. & Turnbull III, H.R. (2004) Access to health care for individuals with developmental disabilities from minority backgrounds. *Mental Retardation*, 42(6), 459-470.
- Report on the health status of the residents of Ontario* (2000). In Johnson I., Ontario. and Ontario. (Eds.), . [Toronto]: Public Health Research.
- Romer, M., Dougherty, N., & Amores-Lafleur, E. (1999). Predoctoral education in special care dentistry: Paving the way to better access? *ASDC Journal of Dentistry for Children*, 66(2), 132-5, 85.
- Royal College of Dental Surgeons of Ontario. (2005). Retrieved June 22, 2007, from [http://www.rcdso.org/about\\_us/statistics.html](http://www.rcdso.org/about_us/statistics.html)
- Russell, G. M., & Kinirons, M. J. (1993). A study of the barriers to dental care in a sample of patients with cerebral palsy. *Community Dental Health*, 10(1), 57-64.
- Sanmartin, C., Houle, C., Berthelot, J.M., White, K. (2002). *Access to health care services in Canada, 2001*. Statistics Canada Catalogue no. 82-575-XIE, Ottawa. Retrieved December 15, 2007, from <http://www.statcan.ca/english/freepub/82-575-XIE/2002001/pdf/report.pdf>
- Seigal, M. D. (1985). Dentists' reported willingness to treat disabled patients. *Special Care Dentist*, 5, 102.
- Shosenberg, J. W. (2001). Dentists are tired of subsidizing government dental programs. *Ontario Dentist*, 5.
- Shuman, S. K., & Bebeau, M. J. (1994). Ethical and legal issues in special patient care. *Dental Clinics of North America*, 38(3), 553-575.
- Statistics Canada. (2001). *A profile of disability in Canada 2001. PALS survey*. Retrieved March 30, 2007, from <http://www.statcan.ca.myaccess.library.utoronto.ca/english/freepub/89-577-XIE/pdf/89-577-XIE1001.pdf>

- Statistics Canada. (2007). *Participation and activity limitation survey 2006: analytical report*. Statistics Canada Catalogue no. 89-628-XIE, Ottawa. Retrieved January 4, 2008, from <http://www.statcan.ca/english/freepub/89-628-XIE/89-628-XIE2007002.pdf>
- Status report on the report of the task force on community dental services for the mentally retarded and physically handicapped, September 1980.*(1980). Ministry of Community and Social Services. Ontario.
- Steifel, D. J. (1981). Delivery of dental care to the disabled. *Journal of the Canadian Dental Association*, 47, 657.
- Stevens, A., & Sinton, J. (2001). Factors influencing dental service utilization in Ontario. Data from the 1996/97 Ontario health survey. *Ontario Dentist*, 23.
- Strayer, M., Kuthy, R., & Sutton, S. (1993). Elderly non-respondents to a mail survey: A telephone follow-up. *Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry*, 13(6), 245-248.
- Survey of dental practice VIII. number of patients and patient visits: Usual length of patient appointments. reports of councils and bureaus. 8. (1972). *Journal of the American Dental Association*, 85(1), 154.
- Survey of non-institutionalized physically handicapped persons in Ontario : Socio-demographic and need-related characteristics.*(1982). In Ontario. (Ed.). [Toronto]: Ministry of Health.
- Tesini, D. A., & Fenton, S. J. (1994). Oral health needs of persons with physical or mental disabilities. *Dental Clinics of North America*, 38(3), 483-498.
- Tiller, S., Wilson, K. I., & Gallagher, J. E. (2001). Oral health status and dental service use of adults with learning disabilities living in residential institutions and in the community. *Community Dental Health*, 18(3), 167-171.
- U.S. Army Center for Health Promotion and Preventive Medicine. (2007). *Dental treatment time by dental classification*. Retrieved June 22, 2007, from <http://chppm-www.apgea.army.mil/dhpw/oralfitness/dentalreatmenttime.pdf>
- Veteran Affairs Canada. (1999). *Dental services*. Retrieved June 22, 2007, from <http://www.vac-acc.gc.ca/general/sub.cfm?source=services/poc/poc4>
- Waldman, H. B., & Perlman, S. P. (2000). Providing general dentistry for people with disabilities: A demographic review. *General dentistry*, 48(5), 566-9; quiz 570-1.

- Waldman, H. B., & Perlman, S. P. (2001). Children with both mental retardation and mental illnesses live in our communities and need dental care. *ASDC Journal of Dentistry for Children*, 68(5-6), 360-5, 302.
- Waldman, H. B., & Perlman, S. P. (2002). Dental care for individuals with developmental disabilities is expensive, but needed. *Journal of the California Dental Association*, 30(6), 427-432.
- Williston, W. B. (1971). In Ontario. (Ed.), *Present arrangements for the care and supervision of mentally retarded persons in Ontario*. [Toronto]. Ontario Dept. of Health, 1971.: Ontario Dept. of Health.
- Wilson, K. I. (1992). Treatment accessibility for physically and mentally handicapped people--a review of the literature. *Community Dental Health*, 9(2), 187-192.
- World Health Organization. (2001). *ICF introduction. ICF: International classification of functioning, disability and health*. Retrieved March 30, 2007, from <http://www.who.int/classifications/icf/site/intros/ICF-Eng-Intro.pdf>
- World Health Organization. (2006). *Concept paper: World report on disability and rehabilitation*. Retrieved June 22, 2007, from [http://www.who.int/disabilities/publications/dar\\_world\\_report\\_concept\\_note.pdf](http://www.who.int/disabilities/publications/dar_world_report_concept_note.pdf)
- Zarfas, D. (1976). Ontario. In R. B. Kugel, & A. Shearer (Eds.), *Changing patterns in residential services for the mentally retarded*. (Revised Edition ed., pp. 267). Washington D.C.: U.S. Government Printing Office.

## APPENDIX A

### Text box 4

#### Types of disabilities among children

The Participation and Activity Limitation Survey (PALS) survey questions allow the identification of the following types of disabilities among children under 15:

**Hearing\***: Difficulty hearing.

**Seeing\***: Difficulty seeing.

**Speech\*\***: Difficulty speaking and/or being understood.

**Mobility\*\***: Difficulty walking. This means walking on a flat firm surface, such as a sidewalk or floor.

**Agility<sup>1\*\*</sup>**: Difficulty using hands or fingers to grasp or hold small objects, such as a pencil or scissors.

**Learning\*\***: Difficulty learning due to the presence of a condition, such as attention problems, hyperactivity or dyslexia, whether or not the condition was diagnosed by a teacher, doctor or other health professional.

**Developmental delay\*\*\***: Child has a delay in his/her development; a physical, intellectual or another type of delay.

**Developmental disability or disorder\*\***: Cognitive limitations due to the presence of a developmental disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth.

**Psychological\*\***: Limited in the amount or kind of activities that one can do due to the presence of an emotional, psychological or behavioural condition.

**Chronic condition\***: Limited in the amount or kind of activities that one can do due to the presence of one or more chronic health conditions that have lasted or are expected to last six months or more and that have been diagnosed by a health professional. Examples of chronic conditions are asthma or severe allergies, heart condition or disease, kidney condition or disease, cancer, epilepsy, cerebral palsy, Spina Bifida, Cystic Fibrosis, Muscular Dystrophy, Fetal Alcohol Syndrome, etc.

**Other<sup>2\*</sup>**: The type of disability is 'other' if the respondent answered YES to the general questions on activity limitations, but did not provide any YES to the questions about type of disability that followed.

- 
1. In 2006 the disability type 'dexterity' was renamed 'agility'.
  2. In 2006 the disability type 'unknown' was renamed 'other'.

\* Applicable to all children under 15

\*\* Applicable to children aged 5 to 14

\*\*\* Applicable to children under 5

Source: PALS Survey, Statistics Canada, 2006.

## APPENDIX B

### Text box 5

#### Types of disabilities among adults

The questions in Participation and Activity Limitation Survey (PALS) enabled us to identify the following types of disabilities in adults (15 years of age or older):

**Hearing:** Difficulty hearing what is being said in a conversation with one other person, in a conversation with three or more persons, or in a telephone conversation.

**Seeing:** Difficulty seeing ordinary newsprint or clearly seeing someone's face from 4 meters away (12 feet).

**Speech:** Difficulty speaking and/or being understood.

**Mobility:** Difficulty walking half a kilometre or up and down a flight of stairs, about 12 steps without resting, moving from one room to another, carrying an object of 5 kg (10 pounds) for 10 metres (30 feet) or standing for long periods.

**Agility:** Difficulty bending, dressing and undressing oneself, getting into or out of bed, cutting own toenails, using fingers to grasp or handling objects, reaching in any direction (for example, above one's head) or cutting own food.

**Pain:** Limited in the amount or kind of activities that one can do because of a long-term pain that is constant or reoccurs from time to time (for example, recurrent back pain).

**Learning:** Difficulty learning because of a condition, such as attention problems, hyperactivity or dyslexia, whether or not the condition was diagnosed by a teacher, doctor or other health professional.

**Memory:** Limited in the amount or kind of activities that one can do due to frequent periods of confusion or difficulty remembering things. These difficulties may be associated with Alzheimer's disease, brain injuries or other similar conditions.

**Developmental disabilities:** Cognitive limitations due to an intellectual disability or developmental disorder such as Down's syndrome, autism or an intellectual disability caused by a lack of oxygen at birth.

**Psychological:** Limited in the amount or kind of activities that one can do due to the presence of an emotional, psychological or psychiatric condition, such as phobias, depression, schizophrenia, drinking or drug problems.

**Other<sup>1</sup>:** The type of disability is 'other' if the respondent answered YES to the general questions on activity limitations, but did not provide any YES to the questions about type of disability that followed.

---

1. In 2006 the disability type 'unknown' was renamed 'other'.

Source: PALS Survey, Statistics Canada, 2006.

## APPENDIX C

### Sample of Questionnaire



UNIVERSITY OF TORONTO  
Faculty of Dentistry

### ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES

**Investigator:** Dr. Anjani Koneru

**Supervisor:** Dr. Michael Sigal

**Sponsor:** Faculty of Dentistry, University of Toronto

**Dear Madam or Sir:**

I am writing to you to ask for your help in a study conducted by the University of Toronto about access to dental care for people with disabilities. If you are a person with a disability or a caregiver for a person(s) with a disability we are in great need of your assistance.

**Purpose:** The purpose of the study is to find out if barriers exist which make it difficult for people with disabilities to access dental care in Ontario. Enclosed is a short questionnaire, asking questions about what challenges, if any, you as a person with a disability or you as a caregiver for a person with a disability face in obtaining dental care in Ontario. The questionnaire/survey is also available on the internet at <http://www.utoronto.ca/dentistry/facultyresearch> (look for the survey under "research news") or the direct link is <http://www.zoomerang.com/survey.zqi?p=WEB225KANLVXAY> and can be submitted online. If you are interested in helping us with our study, we kindly ask you to answer the questionnaire. Your answers are completely **confidential**. This letter has been sent to you by an organization of which you are a member. The organization has mailed this questionnaire to you at our expense. For privacy reasons we have no knowledge or record of your name or address. All information collected will be destroyed after completion of the study.

**Consent to Participate:** We recommend that the questionnaire only be completed with the consent of the person with a disability (who is able to make his/her own legal decisions) or a legal guardian. We assume that questionnaires which have been completed and returned to us, have obtained such consent.

The results of this study will be used to guide provincial and federal government agencies in improving access to dental care for people with disabilities in Ontario and across Canada.

**Risks:** There is no risk or direct benefit in participating.

**If you would like to give us your input, please complete the questionnaire online or return it to us in the pre-stamped self-addressed envelope provided. We ask you to mail it as soon as possible, preferably no later than January 2007.**

If you have any questions or concerns please, feel free to contact me, Anjani Koneru at (416) 979-4750 ext. 3030 or by email at [a.koneru@utoronto.ca](mailto:a.koneru@utoronto.ca). For information on dental services available for people with disabilities please contact: Ontario Dental Association (416) 922-3900, Hospital for Sick Children (416) 813-7433, Children's Hospital of Eastern Ontario (613) 737-2222, and Children's Hospital of Western Ontario (519) 685-8484, Mount Sinai Hospital (416) 586-5147.

Thank you for your time and consideration

Sincerely,  
Anjani Koneru D.M.D.  
Graduate Student, Paediatric Dentistry

Michael J. Sigal, D.D.S., Dip. Paedo., M.Sc., F.R.C.D(C)  
Head, Discipline of Pediatric Dentistry  
Department of Clinical Sciences

## ACCESS TO DENTAL CARE FOR PERSONS WITH DISABILITIES

1

**Part I.****Instructions:** Mark an "X" to answer the following questions:

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

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

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

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

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

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

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

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

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

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

\_\_\_ group home \_\_\_ institution \_\_\_ Other(Specify): \_\_\_\_\_

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

\_\_\_ Autism

\_\_\_ Developmental Delay

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

\_\_\_ Down Syndrome

\_\_\_ Cerebral Palsy

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

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

\_\_\_ YES \_\_\_ NO

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

\_\_\_ YES \_\_\_ NO

10. Do you, the person with the disability, or the person you care for have private dental insurance?  
 YES  NO
11. If you or the person you care for does not have private insurance, but dental care is paid for by a government-sponsored program, please indicate which program:  
 Ontario Disability Support Program (ODSP)  Ontario Works (OW)  
 Children in Need of Treatment (CINOT)
12. What types of dental treatment have you or the person you care for received in the past?  
 Examination  Fillings  Braces or Appliances  
 X-rays  Extractions  Dentures or Partial Denture  
 Fluoride  Sealants  Bleaching  
 Cleaning  Oral Hygiene Instruction  Root Canals  
 Esthetic Crowns/Bridges  Stainless Steel Crowns  Dental Implants
13. When was your, or the person you care for's, last dental visit?  
 within one year  greater than one year
14. What was the overall length of time of your or the person you care for's last dental appointment? Please check the appropriate box.
- |                      | Under 30 min | 30 min-1hr | 1hr-2hr | Other (Specify) |
|----------------------|--------------|------------|---------|-----------------|
| Time in waiting room |              |            |         |                 |
| Time with hygienist  |              |            |         |                 |
| Time with Dentist    |              |            |         |                 |
15. If you or the person you care for has a regular dentist:
- a. How often do you or the person you care for go?  
 emergency only  every 3 mos.  every 6 mos.  every 12 mos.  
 Other (please specify) \_\_\_\_\_
- b. How far is the dentist from your or the person you care for's place of residence?  
 within 10 km  within 10-50 km  within 50-100 km  greater than 100 km
- c. Is the dentist:  
 a General Dentist  a Specialist?
- d. Is the dental clinic a:  
 private office  public community health clinic  hospital?
16. Do you or the person you care for have difficulty communicating dental pain?  
 YES  NO

Go to last page →

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

- No  
 Sedation  
 General Anesthetic  
 Special Chair, Backrest, Headrest
- Protective Support or Restraint  
 Wheel chair transfer  
 Other (Please list: \_\_\_\_\_)

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

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

**Part II. Instructions:**

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

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

- Strongly Disagree  
  Disagree  
  Indifferent  
  Agree  
  Strongly Agree

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

THE END

## APPENDIX D

Geographic locations based on postal codes starting with N, K, L, M, P:

### N = Western Ontario

West Haldimand, Dunnville, Kitchener, Baden, London, Goderich, Wallaceburg, Windsor, Wellington, Elmira, Delhi, Georgian Bay Southwest Shore, Guelph, Cambridge, Ingersoll, Brant and Norfolk, Huron, Tillsonburg, Strathroy, Bruce Peninsula, Aylmer, Leamington, La Salle, Oxford, Waterloo, Perth, Owen Sound, Tecumseh, Elgin, Paris, Port Stanley, Chatham, Middlesex, Fergus, Essex, Lambton, Hanover, Kent, Brantford, St. Thomas, Woodstock, Sarnia, Amherstburg, Caledonia, Listowel, St. Mary's, Simcoe, Kingsville, Kincardine.

### K = Eastern Ontario

Ottawa, Hawkesbury, Smiths Falls, Pembroke, Cobourg, Prescott and Russell United Counties, Stormount, Dundas and Glengary United Counties, Carleton Place, South Leeds and Grenville United Counties, Rideau Lakes area, Gananoque, Frontenac County, Addington County, Loyalist Shores, Cornwall, Perth, Petawawa, Peterborough, Renfrew County, Lanark Highlands Township, Quinte Shores, Rockland, Kingston, Kawartha Lakes and Haliburton County, Belleville, Amherstview, Napanee, Amprior, Brockville, Trenton, Lindsay, Elizabethtown.

### L = Central Ontario

Northumberland County, Port Hope, Fort Erie, Stouffville, Mississauga, Maple, Brampton, Hamilton, East and West Durham Region, Bowmanville, Welland, Richmond Hill, Markham, King City, Lake Simcoe, Courtice, Niagara Falls, Bolton, Queensville, Oshawa, Aurora, Georgetown, Ancaster, Whitby, Woodbridge, Oakville, Dundas, North Peel Region, Thornhill, Acton, Port Colborne, Concord, Caledon Village, Burlington, Port Perry, Georgian Bay (Angus), St. Catharines, Grimsby, Barrie, Penetanguishene, Dufferin, Holland Landing, Halton Region, Keswick, Uxbridge, East Haldimand County, Midland, Alliston, Ajax, Innisfil, Milton, South Glenridge / East Power Glen / Riverview / Marsdale / Brockview / Barbican Heights / Burleigh Hill / West Merriton), Pickering, Orillia, Orangeville, Newmarket, Bradford, Wasaga Beach.

### M = Metropolitan Toronto

North York, Downtown Toronto, Etobicoke, Scarborough, Don Mills, East York, York, East Toronto, West Toronto, Downsview, Willowdale, Central Toronto, Weston.

### P = Northern Ontario

Nipissing, North Bay, Parry Sound, Sudbury, Elliot Lake, Sault Ste. Marie, Thunder Bay, Fort Frances, Sturgeon Falls, Huntsville, Timiskaming, Cochrane, Bracebridge, Algoma & Sudbury District, Timmins, Kirkland Lake, Kapuskasing, Dryden, Kenora, Manitoulin, Gravenhurst, Lake Superior East Shore, Lake Superior North Shore, Sioux Lookout, Northwestern Ontario (Red Lake), Rainy River Region, Lake of the Woods.