Alberta Committee of Citizens with Disabilities

Barrier-Free Health and Medical Services in Alberta

Understanding the Needs of Albertans with Disabilities

Barrier-Free Health and Medical Services in Alberta

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TABLE OF CONTENTS

TABLE OF FIGURES

Executive Summary

The Disability Rights Movement of the 1950s and 1960s in Canada was a response to negative stereotypes and social biases experienced by people with disabilities. Sally Rogow wrote, "Throughout history, people with disabilities have been the forgotten victims of prejudice and abuse. During the first part of the 20th century, they were assumed to be a threat and a burden to the larger society. Devalued, segregated and isolated in institutions, they were deprived of normal social environments and socially distanced from the larger society."[1] People with disabilities experienced attitudinal, social, environmental, communication, transportation, and educational barriers, as well as vulnerability and abuse.

Throughout the last sixty years, there have been significant improvements to services for people with disabilities. There is more awareness and accessible environments, as well as legislation and court cases that have made slow progress through the years. People with disabilities, their families, and supporters have fought hard to reach equality. Even today, many people with cognitive disabilities continue to experience inappropriate communication materials, while the Deaf and Hard of Hearing are faced with a scarcity of interpretive services necessary for proper communication. Individuals with vision impairments still face barriers, inaccessible environments, and a shortage of resources in alternative formats; and people with mobility impairments struggle with environments that are physically inaccessible to them. Individuals with mental health illnesses face societal labels and inappropriate and scarce supports.

ACCD's *Barrier-Free Health and Medical Services in Alberta* project was an initiative to identify the barriers to health and medical services perceived and experienced by Albertans with disabilities when accessing preventative and ongoing health services. This project consisted of a systematic review of existing literature, and a multi-phase needs assessment of two groups: Albertans with disabilities when accessing health and medical services in Alberta; and health care professionals when providing services to people with disabilities. This enabled the project to achieve the following objectives:

- To identify the perceived barriers of people with disabilities when accessing health and medical services in Alberta.
- To identify the needs of health professionals in the delivery of services to people with disabilities in Alberta.
- To evaluate and develop strategies to remove barriers to health and medical services in Alberta.
- To develop an education and awareness campaign to promote barrier-free health and medical services in Alberta.

The target populations for this project were the following:

- People with disabilities: chronic medical impairments, cognitive impairments, intellectual impairments, mental health and substance abuse, physical impairments, and/or sensory impairments.
- Healthcare professionals: physicians, surgeons, laboratory personnel.

[1] Rogow, Sally. *The Disability Rights Movement: The Canadian Experience*. Retrieved on March 25, 2011, from http://www.internationalsped.com/magazines_articles/The%20Disability%20Rights%20Movement%20Ed.1.pdf

The project had two phases. In the first phase, a systematic literature review was conducted to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the current status of access to health and medical services for people with disabilities. The quality of perceived and received primary care depends on access issues like transportation, office design, ability to use the washrooms, making appointments, time spent with medical professionals, and the knowledge and expertise of health and medical professionals when delivering services. These elements were crucial to the purpose of the *Barrier-Free Health and Medical Services in Alberta* project – to develop recommendations and strategies for creating accessible health care services in Alberta.

Needs Assessment

From April to July 2010, ACCD conducted a multi-part needs assessment of the barriers that people with disabilities experience when accessing health and medical services in Alberta. Given that the literature review indicated the importance of creating health care that is responsive to the needs of all citizens, ACCD considered it essential to solicit input from people with disabilities, not-for-profit organizations, and health care professionals. A balance of urban and rural discussion was sought in the consultations. Despite this diversity, each phase reported similar themes.

Community Consultations

Between May 30 and June 11, 2010, ACCD hosted six community consultations attended by people with disabilities, not-for-profit organizations, government representatives of various funding programs, and family members. The community consultations were about sharing information and exploring the unique barriers that are being faced by Albertans with disabilities when accessing health and medical services. The goals of the consultations were to inform, consult, and involve the public in the development of recommendations for barrier-free health and medical services in Alberta. The consultation process made it possible for ACCD to collect information directly from citizens with disabilities, their families, community agencies, and health care professionals in Alberta.

Community consultations were held at the following locations: Edmonton (May 20, 2010), Calgary (May 31, 2010), Vegreville (June 3, 2010), Rocky Mountain House (June 4, 2010), Lethbridge (June 7, 2010), and Grande Prairie (June 11, 2010). A press release was distributed on April 26, 2010 to inform the media about the project and the community consultations. Information about the consultations was distributed through promotional e-mails, and individuals were asked to register. 114 Albertans attended the community consultations and 109 requested follow-up contact concerning the project.

Generally, participants identified the same key challenges and solutions regardless of location. The most reoccurring challenges were concerns about the health care system and medical professionals, lack of access to health and medical services, and inaccessibility of medical clinics and medical equipment. In addition, issues concerning transportation, information and referral, advocacy, lack of government accountability, and caregiver challenges were discussed.

People with Disabilities Survey

The *People with Disabilities Survey* was filled out by 464 individuals, representing urban, rural, and First Nations perspectives about barriers to health and medical services. The results show that individuals with disabilities have unique needs that should be addressed

by the Alberta health care system. Generally, people are satisfied with the medical care they receive; however, personal statements of the survey participants show that the system has many barriers for people with disabilities. Inaccessible medical clinics, inappropriate medical equipment, and long wait times are just a few of the many issues brought forward by the participants.

Survey participants indicated that they support health professionals that offer and provide services, but survey participants perceived flaws in the health care system. Health professionals are required to follow the policies and procedures that are put in place by the Government of Alberta.

Participants recognized that no general practitioner can have knowledge about all disabilities, so they suggested that there be better communication and relationships between general practitioners and specialists.

In addition, project participants said that the Government of Alberta should support physicians and create a means for medical offices and medical equipment to be made accessible for use by all.

Disability awareness is another area that the survey respondents felt needed improvement. Offering disability awareness sessions on a regular basis for health and medical professionals will create understanding about the various disabilities and the needs of patients with disabilities.

Health Professionals Survey

The *Health Professionals Survey* was developed to assess the knowledge and needs of physicians in Alberta who provide services to people with disabilities. The survey consisted of questions regarding types of practices, numbers of patients with disabilities, physical accessibility, availability of disability-related policies and procedures, and opinions regarding the current state of the health care system, among others.

The health professionals that participated in the survey expressed the need for improvement in accessible services for people with disabilities. Programs and services restructuring, the decrease in funding opportunities, and the limited resources that are available leave few options for physicians. A reoccurring question from health professionals is "who will pay for any changes," and this issue needs to be addressed before the health care system is able to accommodate and provide services to all Albertans who are in need of medical and health care services.

Accessibility Audits

The purpose of this component of the needs assessment was to conduct accessibility audits, according to a pre-established audit tool, to gather information about the accessibility of settings that provide health and medical services to Albertans. The intent was to compare various settings such as community health centers, physician clinics, and locations that provide diagnostic services, and to present information that illustrates current access to health care services for people with disabilities at the audited sites.

The ACCD *Barrier-Free Health and Medical Services Audit Tool* was developed from the following sources: section 3.8 (in addition, referencing sections 3.3, 3.4 and 3.5) of the 2006 Alberta Building Code, which deals specifically with barrier-free design for people with

disabilities; the Hotel Association of Canada's *Access Canada Property Standards Manual*; and a paper titled *Making Our Offices Universally Accessible: Guidelines for Physicians*, which was published in the Canadian Medical Association Journal in 1997.

ACCD submitted 41 audit requests to five health care service delivery settings in the province between May 11 and September 20, 2010; however, ACCD only received permission from seven locations. The remaining number of sites declined to participate in ACCD's project. In December 2010, ACCD received a requested to audit three diagnostic clinics, which were completed in January 2011.

ACCD's accessibility audits revealed that there are numerous barriers to health and medical services in Alberta. Individuals are prevented from entering medical offices because of inaccessibility and a lack of adherence to the Alberta Building Code.

Also, the site audits revealed that site managers are cognizant of the various barriers; however, limited funding allocations and current policies lead, in many cases, to processes and procedures that are limiting for patients with disabilities. In addition, there was an evident lack of written policies and procedures about provision of care to patients with disabilities.

Existence of barriers to health and medical services in Alberta
Despite the diversity of participants present at each phase, each needs assessment section reported similar themes. Most notably, all needs assessment phases reported that there are barriers in the health care system – barriers that are being created as a response to current policymaking without seeking input from patients and health care professionals.

Participants overwhelmingly presented the need for a diverse range of services and for the government to assist health care professionals to provide these services in an appropriate and timely manner. Every consulted location has been significantly affected by current government restructuring of services and lack of funding opportunities.

Recommendations for the establishment of barrier-free health and medical services in Alberta
The results of the *ACCD Barrier-Free Health and Medical Services in Alberta* project cannot be summed up in a single overarching recommendation for creating barrier-free health and medical services. The literature review, the community consultations, and the questionnaires filled out by people with disabilities and health professionals portrayed a picture of complexity – a health services delivery system that depends on budgets, human resources, and the needs of the population it serves. The challenge is how to establish a proficient health care system and meet the funding requirements that will follow.

ACCD developed recommendations based on the findings from the needs assessment phase of the project. The recommendations have been categorized under system-wide improvement recommendations and disability-specific recommendations.

System-Wide Improvement Recommendations

Under system-wide improvements, the following recommendations were developed to enhance the Alberta health care system service delivery:

Disability Awareness and Education
Disability awareness and education is crucial for establishing a foundation for barrier-free health and medical services in Alberta. Comments received from participants at the community consultations and from the online questionnaires stated that health professionals' lack of knowledge about disabilities acts as a roadblock to people with disabilities when accessing health and medical services.

The following recommendations will contribute toward higher disability awareness:

- Develop effective strategies to raise awareness about the health care needs of people with disabilities.
- Create a program that will distinguish health care professionals who excel beyond their duties to assist patients with disabilities.
- Establish a patient-centred system where the patient will be considered a part of the decision-making team

Service Delivery
Project participants stated that it is vital for services to be delivered when needed rather than after long-waiting periods.

The following recommendations will contribute toward establishing an efficient service delivery system:

- Establish an effective compensation system that will allow health care professionals to assist people with disabilities in a suitable and timely manner.
- Establish protocols and resources for health care professionals to develop written reports when considered essential for diagnosis and treatment of patients with disabilities.
- Appointments should be according to patient need (shorter for prescription renewal and longer for more complex needs).
- Allow, in extreme cases, home visitations by health care professionals.
- Create incentives to allow health professionals to develop care manuals.
- Create a tool that will allow disability knowledge sharing among health care professionals, such as establishing an electronic knowledge database.
- Provide incentives to recruit more specialists (e.g. autism spectrum disorders) in adult services.
- Develop a system that is proactive and focused on preventative services.

Rural Health Care Service Delivery
Patients with disabilities in rural areas are not able to access timely services because of an insufficient number of doctors and specialists providing services.

The following are proposed recommendations for improvement in rural health service delivery:

- Establish infrastructure for health services in rural areas so people can access services in their communities.
- Allocate resources for services in rural areas to perform day surgeries which will reduce waiting times and people will be able to receive timely and appropriate services in their own communities.

- Set up more frequent specialized traveling clinics for diagnostic tests.
- Eliminate the pay scale difference between urban and rural doctors.
- Create a plan of how to contract more health professionals to move to rural areas and remain long term.
- Establish medical teams with various specialists in every community.

Transition to services

At each consultation and in many survey responses, an issue that was commonly cited was the lack of transition from child to adult services. Once children turn 18, the support system is no longer effective or efficient.

Extensive transition planning has to be conducted to achieve the following:

- Ease the transition from children's health services to adult's health services.
- The transition of services between age 16 to 65 to 65 and over should be connected and seamless for the individual in the system.

Collaborations

ACCD project participants stated that there is a disconnect between various ministries and health departments in Alberta. Participants said they have to navigate through a system that does not include the opinion of the patient. The following collaborations are crucial:

- Establish collaborative initiatives between health professionals, Alberta Health Services, and Alberta Health and Wellness.
- Establish doctor-patient collaborative initiatives.

Decision making

There is a perception that patients are never consulted when changes are being considered and/or implemented.

The findings from the ACCD *Barrier-Free Health and Medical Services in Alberta* project indicate a need for the following:

- Patients with disabilities should be an integral part of the decision-making medical team.
- Decision-makers must understand the diversity of each community in Alberta. Many locations such as Lethbridge and Grande Prairie are still considered rural when services are allocated.

Information and referral

Significant frustration comes from the inability of patients to find appropriate and necessary information. Patients are being sent from one point of entry to another without success. It is crucial for the government to do the following:

- Establish a coordinated information system that will guide patients and their families toward appropriate and timely services. Even though there are various initiatives, such as the Health Link Information Line, many patients are unaware of these information and referral systems.
- Community organizations should act as information and referral resources.

Accessible offices and equipment
Accessibility is essential not only for patients with disabilities, but also for seniors and parents with children. Decision makers must establish polices that will maintain and encourage the following recommendations:

- New health care facilities should comply with and go beyond the Alberta Building Code.
- Develop standards that will guide health and medical professionals when establishing accessible offices.
- Provide incentives for health care professionals to establish practices in accessible offices.
- Mandate a minimum number of accessible exam rooms per number of patients or health care professionals.
- Mandate one fully accessible facility where people with disabilities can go to receive appropriate and adequate medical care.
- Update medical equipment to reflect the needs of the population. When developing policies regarding medical equipment, there should be consideration given to universally usable equipment. Equipment should be used by the maximum number of people.

Patient Education
According to the survey participants, many of the issues arise from patients with disabilities not having proper education about preventative and ongoing health care services and procedures. Establishing educational campaigns for patients with disabilities to learn about their responsibilities and the services available would assist them to become active participants in their health care needs. These educational campaigns could be successfully administered and delivered by community organizations that already assist people with disabilities to understand the health care system.

Disability-Specific Recommendations
The following recommendations address the particular challenges that are experienced by people with various impairments.

Hearing Impairment: Service Delivery Recommendations
- Provide disability awareness programs about the specific needs of individuals with hearing impairments.
- Establish protocols and standards for American Sign Language interpreting services when accessing health and medical services in Alberta.
- Provide education and awareness about the communication needs of individuals who are hard of hearing or deaf.
- Provide incentives for training and usage of communication technology.

Seeing Impairment: Service Delivery Recommendations
- Provide disability awareness programs about the specific needs of individuals with seeing impairments.
- Establish standards and requirements for better signage in health care facilities.
- Provide health care information in alternative forms of communication.

Speech Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with speech impairments.
- Allow health care professionals to allocate extra appointment times for individuals with speech impairments, as proper communication is imperative for diagnosis and treatment.

Pain Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with pain impairments.
- Establish a system that will address the need for shorter waiting times.
- Implement and practice an holistic approach to illness management.
- Improve patient-doctor communication.

Learning Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with learning impairments.
- Establish communication resources between patients with learning impairments and health care professionals.

Mobility and Agility Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with mobility and agility impairments.
- Enhance collaborations between general practitioners and specialists when treating patients with mobility and agility impairments.
- Mandate the development of accessible health care clinics and facilities, and the purchase of accessible medical equipment.
- Focus on preventative care.

Memory Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with memory impairments.
- Enhance the follow up system for patients with memory impairments.

Developmental Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with developmental impairments.
- Establish efficient access to patient information.
- Recruit specialists who can treat adults with Autistic Spectrum Disorders and other developmental impairments.

Psychological (mental) Impairments: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with psychological (mental) impairments.
- Create a system that will focus on appropriate and timely mental health services.
- Provide services with respect and dignity.
- Establish appropriate communication methods with individuals with psychological (mental) impairments.

- Provide patient education and appropriate information and referral services.
- Create awareness about the side effects of diagnosis and treatment.

Multiple Impairments: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with multiple impairments.
- Allocate extra appointment times for multiple diagnosis and treatments.
- Train health care professionals about multiple diagnosis patients.
- Use an holistic approach to care.
- Develop efficient access to new treatments and therapies.

Conclusion

As Patricia Benner writes, "our moral sensibilities and possibilities in relation to our lifesaving technologies will require more than the objectified clinical vocabularies and clinical language that we presently use. Perhaps such development cannot be accomplished without some public space for weeping and for considering illness and death as human passages and not just clinical courses of disease."[2]

ACCD's position in the disability community, and its ability to engage health care professionals and government underlie the successful completion of each phase of this project. The recommendations offered would not have been possible without collaboration from people with disabilities, community agencies, health care professionals, and government decision-makers.

The recommendations are based on the findings from the *ACCD Barrier-Free Health and Medical Services in Alberta* project. We strongly believe that evidence-based solutions can create a system where all patients can receive proper medical care. "Evidence-based decision-making as the 'foundation for an effective and efficient health system' has been endorsed by a number of Canadian Health Organizations including Health Canada and the Canadian Health Services Research Foundation."[3]

ACCD acknowledges the complexity of the issues and that many of the solutions require financial investment; however, implementing these recommendations will create cost-effective strategies by reducing the number of individuals with disabilities accessing long-term care facilities.

Albertans with disabilities are passionate about health care issues, and they contributed to the development of the recommendations for barrier-free health and medical services in Alberta. Moving forward, the intent of the project will be to assist decision-makers to produce policies that will have the greatest impact on the lives of people with disabilities.

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[2] Benner, P. (2004). Seeing the Person beyond the Disease. *American Journal of Critical Care January 2004, Volume 13, No. 1.* Retrieved on March 8, 2010, from http://ajcc.aacnjournals.org/cgi/reprint/13/1/75

[3] Armitage, G. et al. (2009). *Health Systems Integration: State of the Evidence*. *International Journal of Integrated Care – Vol. 9, 17 June 2009*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707589/pdf/ijic2009-200982.pdf

Introduction: Project Scope

Project Overview

ACCD's *Barrier-Free Health and Medical Services in Alberta* project was an initiative to identify barriers to health and medical services perceived and experienced by Albertans with disabilities when accessing preventative and ongoing health services.

The project had two phases. In the first phase, a systematic literature review was conducted to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the current status of access to health and medical services for people with disabilities.

In order to gain insight into personal experiences, ACCD distributed a questionnaire to people with disabilities and health care professionals. In addition, ACCD hosted community consultations in Calgary, Edmonton, Grande Prairie, Lethbridge, Rocky Mountain House, and Vegreville.

During the second phase, ACCD developed a communication and educational media campaign for disseminating the project findings and recommendations to medical professionals, the disability community, and the general public.

Purpose

Avedis Donabedian[4] wrote that health care should be safe, effective, patient-centered, timely, efficient, and equitable in order to reach optimal levels of health care quality. "The criteria of quality are nothing more than value judgments that are applied to several aspects, properties, ingredients or dimensions of a process called medical care. As such, the definition of quality may be almost anything anyone wishes it to be, although it is, ordinarily, a reflection of values and goals current in the medical care system and in the larger society of which it is a part."[5] It is clear that quality of care depends on the information available and used to assess the needs of the patients. For people with disabilities, "the questions of access and quality of primary care are intimately connected."[6]

The quality of perceived and received primary care depends on access issues like transportation, office design, ability to use the washroom, making appointments, time spent with medical professionals, and knowledge and expertise of health care and medical professionals when delivering services. These elements are central to the *Barrier-Free Health and Medical Services in Alberta* project, and findings regarding these elements guided the development of ACCD's recommendations and strategies for creating accessible health care services in Alberta.

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[4] Donabedian's three volume book set on the "Explorations in quality assessment and monitoring" (1980–1985) is a monumental contribution to health care quality. He articulated seven pillars of quality as being: efficacy, efficiency, optimality, acceptability, legitimacy, equity, and cost. His contributions to health care quality include addressing issues such as access to health care, measuring and evaluating health care quality, completeness and accuracy of medical records, observer bias, patient satisfaction, and cultural preferences in health care. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1743903/pdf/v013p00472.pdf

[5] Donabedian, Avedis. (2005). Evaluating the Quality of Medical Care. *The Milbank Quarterly, Vol. 83, No. 4, 2005 (pp. 691–729).* Retrieved on March 8, 2010, from www.milbank.org/quarterly/830416donabedian.pdf

[6] Branigan, M. et al. (2001). Perceptions of Primary health care Services among Persons with Physical Disabilities. Part 2: Quality Issues. *Medscape General Medicine. 2001; 3(2)*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/408123

Objective

The *Barrier-Free Health and Medical Services in Alberta* project had the following objectives:

- To identify the perceived barriers of people with disabilities when accessing health and medical services in Alberta.
- To identify the needs of health professionals in the delivery of services to people with disabilities in Alberta.
- To evaluate and develop strategies to remove barriers to health and medical services in Alberta.
- To develop an education and awareness campaign for the development of barrier-free health and medical services in Alberta.

These objectives were achieved using the following methods: a systematic review of existing literature; and a multi-phase assessment of the needs of Albertans with disabilities when accessing health and medical services, as well as the needs of health care professionals when providing services.

Framework

This project approached access to and delivery of health and medical services as cited by the Canadian Health Care Act and provincial legislation.

This approach allowed the following:

- Recommendations to be developed that will serve as a guide for barrier-free health and medical services in Alberta.
- People with disabilities will be able to fully participate in the health and medical services system in Alberta.
- Creation of a system that is equal and equitable for all citizens. This system will not only benefit people with disabilities, but any Albertan who, at some point in his or her life, may acquire a short- or long-term disability, seniors and those with age-related disabilities, and people who will be accessing health and medical services in a community setting (e.g., diagnostic labs, doctors' offices, etc.), as the focus is enhancement of community-based health and medical services.

Report Outline

The following section describes the systematic literature review process and highlights the findings in regard to barriers to health care services, previously conducted studies, various court cases, and established practices in eliminating barriers for people with disabilities when accessing the health care system.

The following section also reports on each needs assessment of perceived and experienced barriers by people with disabilities, and the perspectives of health care professionals when delivering health care services.

Following the needs assessment results, the report includes a discussion identifying common themes in the areas of access to health and medical services in Alberta, as identified during the literature review, community consultations, surveys, and case studies.

The report's final section presents recommendations for the establishment of barrier-free health and medical services in Alberta. These recommendations are guided by the findings from the community consultations, surveys and accessibility audits.

Systematic Literature Review: The Process

A systematic review of literature was conducted with the rationale of synthesizing contemporary studies, policies, case studies, government initiatives, legislation, opinions, and grey literature on the current state of access to health and medical services for people with disabilities. [7] This synthesis of literature included both qualitative and quantitative data produced by various organizations and institutes.

Databases

For the systematic literature review the following search databases were used:

- *Canadian Institute for Health Information* – "CIHI is responsible for many databases and registries that capture information across the continuum of health care services in Canada. This information supports research and analysis for planning and policy making purposes."[8]
- *Medscape* – "Medscape from WebMD offers specialists, primary care physicians, and other health professionals the Web's most robust and integrated medical information and educational tools."[9]
- *Medical Literature Analysis and Retrieval System MEDLARS/ MEDLINE* - is the "U.S. National Library of Medicine's (NLM) premier bibliographic database that contains over 16 million references to journal articles in life sciences with a concentration on biomedicine."[10]
- *PubMed* – "comprises approximately 20 million citations for biomedical literature from MEDLINE, life science journals, and online books. PubMed citations and abstracts include the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and preclinical sciences. PubMed also provides access to additional relevant Web sites and links to the other NCBI molecular biology resources."[11]
- *Entrez* – "the Entrez Global Query Cross-Database Search System is a powerful federated search engine, or web portal that allows users to search many discrete health sciences databases at the National Center for Biotechnology Information (NCBI) website. NCBI is part of the National Library of Medicine (NLM), itself a department of the National Institutes of Health (NIH) of the United States."[12]
- *BioInfoBank Library* – "this site is aimed at supporting and promoting the scientific activity of students and scientists."[13]

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[7] Armitage, G. et al. (2009). Health Systems Integration: State of the Evidence. *International Journal of Integrated Care – Vol. 9, 17 June 2009*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707589/pdf/ijic2009-200982.pdf
[8] Canadian Institute for Health Information. *Web Site*. Retrieved May 15, 2010, from http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_e
[9] Medscape. *Web Site*. Retrieved May 15, 2010, from http://www.medscape.com/public/about
[10] National Library of Medicine. *Web Site*. Retrieved May 15, 2010, from http://www.nlm.nih.gov/pubs/factsheets/medline.html
[11] PubMed. *Web Site*. Retrieved on May 15, 2010, from http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=helppubmed&part=pubmedhelp#pubmedhelp.FAQs
[12] Entrex. *Web Site*. Retrieved on May 15, 2010, from http://www.ncbi.nlm.nih.gov/gquery/gquery.fcgi
[13] BioInfoBank Library. *Web Site*. Retrieved on May 15, 2010, from http://lib.bioinfo.pl/home/about

- *Wiley InterScience* – "an online service that provides access to over 3 million articles across nearly 1500 journals and 7000 Online Books and major reference works."[14]
- *The Clinics of North America* – "comprehensive, state-of-the-art reviews by experts in the field provide current, practical information on the diagnosis and treatment of conditions that your patients present with every day."[15]

Searched Phrases

The databases were searched with the following phrases:

- People with disabilities and access to health care
- Special needs populations and access to health care
- Barrier free health care
- Barrier free patient room
- Health care services for people with disabilities
- Barrier free access to services
- Universal design
- Barrier free design guidelines
- Health care policies and people with disabilities
- Access to health care
- People with disabilities health care access studies
- Disability policies
- Healthcare in Canada
- Healthcare in Alberta
- Disability legislation
- Duty to accommodate
- Medical imaging technology

Search methods were broad because of the inconsistencies in terminology and classification. Studies used inconsistent terms in describing people with disabilities as "people with disabilities," "disabled people," "special needs people," "people with special needs," "disabled populations," or "special needs populations." The term "accessible" was used to describe monetary value rather than physical accessibility to a place. In addition, there was inconsistency in using terms like "barrier-free" and "universal design," although these two terms have particular definitions.

Target Populations

The following populations were targeted for this project:

- People with disabilities: chronic medical disorders, cognitive disorders, intellectual disorders, mental health and substance abuse, physical disorders, and/or sensory disorders.
- Healthcare professional: physicians, surgeons, laboratory personnel.

[14] Wiley InterScience. *Web Site*. Retrieved on May 15, 2010, from http://www3.interscience.wiley.com/aboutus/
[15] The Clinics of North America. *Web Site*. Retrieved on May 15, 2010, from http://www.theclinics.com/

Annotated bibliography

The systematic literature review produced scholarly articles, reports, books and presentations that were grouped in the following themes for the development of the *Barrier-Free Health and Medical Services in Alberta* project's Annotated Bibliography:[16]

- access to government programs
- access to health care services
- accessibility guidelines
- accessible health facilities
- accessible transportation
- acts
- assistive technology
- consumer involvement in decision making
- consumer satisfaction with health care survey result
- court cases
- defining disability
- demographic information
- design guidelines
- disability policies
- healthcare disparities
- healthcare expenditures
- healthcare models
- healthcare reforms
- healthcare policy framework
- health workforce planning
- healthcare systems
- healthcare indicators
- home care
- impact of the aging population
- independent living
- international classification of functioning, disability, and health
- medical equipment
- people with disabilities
- people with disabilities and health services
- policy research
- primary health care
- proposed acts
- rural health care services
- survey
- universal design
- women and health services
- women with disabilities and health services

The systematic literature review revealed the inconsistencies in terminology and lack of policies for barrier-free health and medical services. Work is being done to address this problem. One medical organization in particular - the Trillium Health Centre[17] - is creating accessible environments and providing information in alternative forms. Studies with the purpose of identifying barriers for people with disabilities lack general population comparative analysis because of out-dated statistical information, non-existence of Stats

[16] The *Barrier-Free Health and Medical Services in Alberta Project Annotated Bibliography* is available in Appendix V.
[17] Trillium Health Centre. (2004). *Creating a Barrier-Free World: Annual Accessibility Plan 2004-2005*. http://www.trilliumhealthcentre.org/about/AccessibilityPlan2004_05_v2.pdf

Canada people with disabilities population specific information, or the inability to secure funds to conduct large comparative studies.

The following section summarizes the findings from the systematic literature review conducted by ACCD.

Systematic Literature Review: A Summary of the Findings

Introduction

According to Dr. Eike-Henner Kluge[18], "for decades, the problem of how to allocate health care resources in a just and equitable fashion has been the subject of concerted discussion and analysis, yet the issue has stubbornly resisted resolution."[19] Decision-making on appropriate allocations has been entwined with human rights, legislation, basic needs, and quality of life. There are various perspectives of how countries should institute their resources and services in health care, depending on the types of patient-physician relationships that are being encouraged and practiced.

How physicians form ongoing relationships with patients with varying needs is an important issue. Also, there are various polices and legislation that influence this relationship, and the question of how much accommodation is appropriate without causing hardship for both the patient and the health care service provider. Governments tend to see health care as a business that requires an enormous amount of assets and monetary allocations, with very few tangible outcomes, while patients tend to see health care as a basic right.[20]

The systematic literature review conducted by ACCD reveals that creating barrier-free health and medical services requires a philosophical shift in how the patient-physician relationship is perceived, and how current legislations are enforced. The findings show that the primary goal of service delivery must be to help people achieve independence, and services must emphasize wellness and prevention. With the aging of the baby boomers and the growing number of people with disabilities in Canada and Alberta, the cost of health care will only increase, and creating sustainability will continue to be one of the most demanding policymaking resolutions.

The Systematic Literature Review: Summary of the Findings section provides a brief overview of the literature review including various studies and court cases in relation to people with disabilities and access to health care services. A systematic review of literature was conducted with the rationale of synthesizing contemporary studies, policies, case studies, government initiatives, legislation, opinions, and grey literature on the current state of access to health and medical services for people with disabilities. [21] This synthesis of literature includes both qualitative and quantitative data and grey literature produced by various organizations and institutes.

People with Disabilities: Defining Consumer-Driven

In the 1970s, people with disabilities began establishing consumer-driven movements that demanded equitable choice and inclusion in the decision-making processes. These movements set out to create theoretical change in the "individualistic conceptualization of

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[18] Professor at the at the University of Victoria, British Columbia,

[19] Kluge, Eike-Henner. (2007). Resource Allocation in health care: Implications of Models of Medicine as a Profession. *Medscape General Medicine. 2007; 9(1):57*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/551802

[20] Kluge, Eike-Henner. (2007). Comparing Health Care Systems: Outcomes, Ethical Principles, and Social Values. *Medscape General Medicine. 2007;9(4):29*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/564144

[21] Armitage, G. et al. (2009). Health Systems Integration: State of the Evidence. *International Journal of Integrated Care – Vol. 9, 17 June 2009*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707589/pdf/ijic2009-200982.pdf

disability by stating that disability stems not from individual limitations but from the failure of the social environment to adjust to the needs of people with different abilities."[22]

These disability rights movements created public awareness about living with a disability. Disability theorists attempted to eliminate labelling of people with disabilities and determine why terms such as "impaired" or "disabled" are used in wrong or negative contexts throughout disability-related research and studies.

"Disability studies are a new approach to understanding disability, arising out of the social movement of disabled people."[23] The World Health Organization (WHO) defines disability "as a medically or psychologically diagnosed condition that restricts a person's functional ability and activity." Impairment is defined as a "medical condition that is the result of an injury, disease, or other disorder which interferes with the structure of the body, producing a reduction in physical or mental ability and activity." Handicap is "an environment and/or social barrier that limits or prevents an individual from fully participating in everyday activities and opportunities."[24] An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.[25]

Disability theorists have been attempting to separate disability from the term impairment, because society tends to use the term disability in order to create a picture of something that is incomplete or broken. People with disabilities are often perceived as broken or unable to fit society's collectively held image of what constitutes a person. The disability rights movements argued that people with disabilities should have the same opportunities in life as able-bodied people, without being placed into categories and segregated, and that being disabled by no means represents a broken individual.

People with disabilities demanded and began to receive respect and equality, and they used these changes towards further empowerment. These "counter-hegemonic politics" sought to eliminate societal ideas that people with disabilities are at the mercy of the able-bodied population and that people with disabilities are a burden to society.[26] These changes intended to eliminate attitudinal and environmental barriers that were and are still experienced by people with disabilities.

The disability movements opposed legislations that limited the abilities of people with disabilities. Perhaps the greatest example of achieved societal change occurred with the abolishment of the 1928 Sexual Sterilization Act of Alberta. More than 3000 individuals were sterilized between 1928 and 1972 because they had disabilities.[27] The Act was repealed in 1972 and ended a dim chapter of Alberta's history, but the effects of this legislation are still felt by many to this day.

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[22] Jongbloed, Lyn. (2003). Disability Policy in Canada: An Overview. *Journal of Disability Policy Studies. Volume: 13. Issue: 4. Publication Year: 2003. Page Number: 203+.* Retrieved on March 8, 2010, from http://www.questia.com/read/5001705967?title=Disability%20Policy%20in%20Canada%3a%20An%20Overview

[23] Shakespeare, T. (1999). The Sexual Politics of Disabled Masculinity. *Sexuality and Disability, 17*(1), 53-64.

[24] World Health Organization. *Disabilities*. Retrieved on March 8, 2010, from http://www.who.int/topics/disabilities/en/

[25] *Ibid*

[26] *Ibid*

[27] Institute of Law and Research and Reform. (1989). *Competence and Human Reproduction*. Retrieved on March 8, 2010, from http://www.law.ualberta.ca/alri/docs/fr52.pdf

In 1996, the Government of Canada agreed to examine the needs of people with disabilities and list gaps in services as one of the government priorities. In 1998, *In Unison: A Canadian Approach to Disability Issues* was jointly released by the Government of Canada and the provinces and territories. This framework document provided a shared vision, principles, and objectives to guide future action on disability issues and policymaking by the federal and provincial governments. In addition, the report defined "objectives for the future development of disability supports: accessibility, portability, and an individual focus."[28]

The Social Union Framework Agreement, signed in February 1999, had the goal of providing definitions and consistency of terminology in the creation of disability-related policies.[29] The vision for this framework was to establish grounds for "full citizenship for all Canadians — including persons with disabilities."[30] The assumption was that if people with disabilities are able to receive proper supports, they will be able to secure employment and become contributing citizens. This report confirmed the complexity in defining *disability* as an identifying label. During the discussions, it became apparent that assessing disability-related terminology was very different than assessing the needs of an individual living with a disability.

In 2003, the Government of Canada produced a document entitled *Defining Disability: A Complex Issue* with the rationale of providing a "framework for understanding, disability definitions in key Government of Canada initiatives." This report highlighted the perplexity that exists between "definitions, eligibility criteria, and program objectives."[31] The problem has always been how to define the term *disability,* and how to create programs that will be responsive to the needs of individuals with disabilities. The report concludes with the following statement:

> "disability is difficult to define because it is a multi-dimensional concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of the socio-economic, cultural and political disadvantages resulting from an individual's exclusion." In addition, "the medical model assumes that disability is an intrinsic characteristic of individuals with disabilities. This assumption translates into practices that attempt to "fix" individuals' abnormalities and defects, which are seen as strictly personal conditions. The functional limitations perspective arose from attempts to expand the medical model to include non-medical criteria of disability, especially the social and physical environment."[32]

The literature review confirmed that defining disability is not a straightforward undertaking. With the intent of creating standardized disability-related measurement tools, countries like Canada, Australia, Italy, India, Japan, and Mexico developed and implemented reporting systems for rehabilitation, home care, and disability impact based on the *International Classification of Functioning, Disability and Health* (ICF).

In 2001, the World Health organization adopted the *International Classification of Functioning, Disability and Health* framework. This framework is used as the "international

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[28] Human Resources and Skills Development. (1999*). Future directions To Address Disability Issues for the Government of Canada: Working Together for Full Citizenship*. Retrieved on March 8, 2010, from http://www.servicecanada.gc.ca/eng/cs/sp/sdc/socpol/publications/reports/1999-000046/page08.shtml

[29] *Ibid*

[30] *Ibid*

[31] Government of Canada. (2003). *Defining Disability: A Complex Issue*. Retrieved on March 8, 2010, from http://dsp-psd.communication.gc.ca/Collection/RH37-4-3-2003E.pdf

[32] *Ibid*

standard to describe and measure health and disability."[33] The goal of ICF is to show that disability is not something that is experienced by a few individuals but it is "universal human experience."[34] This standardized tool has assisted in the development of health standards, disability policies, and various legislations in many countries.[35]

People with Disabilities: Experiencing Barriers

The consumer-driven movements were a response to barriers that were experienced by people with disabilities – barriers ranging from attitudinal, to environmental, communication, transportation, vulnerability and/or violence. Many individuals with cognitive disabilities continue to experience lack of appropriate communication materials, while deaf and hard of hearing individuals are faced with a lack of interpretive services necessary for proper communication. Citizens with vision impairments still face barriers because of the lack of accessible environments and lack of resources in alternative formats. People with mobility impairments are struggling with environments that are inaccessible. Individuals with mental health illness are faced with societal labels and inappropriate supports.

The following section illustrates the findings from the literature review in relation to the barriers that are faced by people with disabilities.

Attitudinal Barriers

The utmost barriers that people with disabilities face today are attitudinal barriers and the implications associated with them. Gerschick writes that "the greatest impediment to a person's taking a full participation in this society are not his physical flaws, but rather the tissue of myths, fears, and misunderstandings that society attaches to them."[36]

In a literature review conducted by the National Disability Authority from Ireland, it became apparent that there is not a universally accepted definition of what attitudinal barriers are and how to classify attitudes.[37] Attitudes affect people with disabilities when seeking employment, education or health care and in their everyday life interactions. This study found that perceptions of the public regarding disability have improved but not toward disabilities that are invisible or unpredictable such as mental health:[38]

> "A major reason proposed for negative social attitudes, resulting in the denial of basic values and rights/conditions, is the way disability is portrayed and interpreted in society. Biklen (1987) and Taylor et al (1993) identified social construction of disability as a barrier to social inclusion. At community level negative attitudes can become structured into social patterns of segregation and discrimination. The theory of social construction attempts to explain the process by which knowledge is created and assumed as reality (Douglas, 1970 cited by Devine, 1997). The theory asserts that meanings are created, learned and shared by people and then reflected in their behaviour, attitudes and language (Devine 1997 citing Berger et al, 1966).

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[33] World Health Organization. *Web Site*. Retrieved on March 8, 2010, from http://www.who.int/classifications/icf/en/
[34] *Ibid*
[35] World Health Organization. *Sample of ICF Checklist Version 2.1a, Clinician Form for International Classification of Functioning, Disability and Health*. Retrieved on March 8, 2010, from http://www.who.int/classifications/icf/training/icfchecklist.pdf
[36] Gerschick, T. J. (2000). Toward a theory of disability and gender. *Signs, 25*(4), 1263.
[37] National Disability Authority. (2006). *Literature Review on Attitudes towards Disability*. Retrieved on September 25, 2010, from http://issda.ucd.ie/documentation/nda/nda06-literature.pdf
[38] *Ibid*

> Particular social constructions of disability portray people with disabilities as "other" and not as an integral part of the 'normal' world. Negative attitudes and behaviours develop from this 'worldview'. In the last two decades disability rights activists and academics have highlighted cultural and environmental factors that marginalise people with disabilities, denying them basic values and the accompanying basic rights/conditions. This social model of disability places a person's impairment in the context of social and environmental factors, which create disabling barriers to participation (Oliver, 1990)."[39]

Attitudinal barriers are created and maintained by the low expectations of what people with disabilities can and cannot do – perceptions that people with disabilities are burdens, a general misunderstanding of what disability is, and the perceived lack of ability that individuals with disabilities have when seeking employment and educational opportunities. Research shows that there is a lack of disability awareness that is effective and impactful.[40] "The root of disability lies in a failure of the environment to allow someone to function to his/her full capacity as much as in any functional impairment that the person may have."[41]

Environmental Barriers

Additional obstacles for people with disabilities are the environmental barriers created by architectural designs that limit accessibility for individuals with mobility or visual impairments. In 1981, Berube wrote, "barrier-free design is not architecture specifically for the disabled. It's simply design that takes into account the wide range of potential users of a building - the temporarily or chronically disabled, the elderly, children, and indeed, the able-bodied making deliveries, carrying groceries, pushing a baby carriage or moving furniture."[42] Elizabeth Brawley states that "physically and mentally challenged individuals become more vulnerable and dependent on their environment to compensate for sensory impairments, including dimming eyesight, which interferes to some degree with daily activities as well as social and leisure activities – the things that provide emotional and social well-being." [43]

The Alberta Building Code is in place to guide the development of structures. Section 3.8 of the code deals with barrier free code criteria and is limited in its application, most notably in private residences and in certain industrial settings. In unique circumstances, contractors and builders are able to apply for relaxation of criteria contained in Section 3.8. In Alberta, code enforcement is the responsibility of municipalities; however, finite financial resources limit the ability of municipal governments to enforce the building code.

There are two important philosophies regarding accessible environments: barrier-free design and universal design. The Government of Alberta defines barrier-free as "the absence of obstacles in an environment, therefore allowing persons with physical, mental or sensory disabilities safer and easier access into buildings and then use of those buildings and related facilities and services."[44]

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[39] *Ibid*
[40] *Ibid*
[41] *Ibid*
[42] Berube, B. (1981*).* Barrier-Free Design – Making the Environment Accessible to the Disabled*. CMA Journal, January 1, 1981, Volume 124*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1705088/pdf/canmedaj01473-0070.pdf
[43] Brawely, Elizabeth. (2009). Enriching Lighting Design*. NeuroRehabilitation 25 (2009) 189–199*. Retrieved on March 8, 2010, from http://iospress.metapress.com/content/t5151v545346x40l/fulltext.pdf
[44] Safety Codes Council. (2008). *Design for Independence and Dignity for Everyone: Vision, Hearing, Communication, Mobility, Cognition – Barrier-Free Design Guide*. Retrieved on September 10, 2010, from http://www.safetycodes.ab.ca/upload/docs/SCC-BFDG-FINAL-protected.pdf

"Universal access or universal design is a concept, that, when applied to environments, ensures that facilities, products, and services are usable by all people."[45] Joines writes that "universal design focuses on selecting products and creating environments in which individuals can use their abilities (senses, strength, coordination, reflexes and sensation) to accomplish tasks without special accommodation."[46] The seven principles of universal design are equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and use.[47]

The disability community has been vocal regarding the need for barrier-free environments and equal access to services. Many organizations, like the Council of Canadians with Disabilities[48] or the Canadian Paraplegic Association, have been demanding implementation and enforcement of the barrier-free building codes and for the establishment of a Universal Design Centre "that would act as a cross-departmental focal point of responsibility to harmonize, track and deliver results in the area of barrier removal."[49]

As Lepofsky and Graham[50] state "there is no entrenched sector of society which would oppose the task of making legislation barrier-free for persons with disabilities."[51] The government has a duty to assure that all legislations, services, and products are accessible to all citizens. "Those who participate in the legislative process cannot consciously or unconsciously assume that all those who will be affected by that legislation have no disabilities now and will never get one."[52] Implementation of barrier-free and universal design principles and concepts must eliminate environmental barriers that are faced by people with disabilities.

Communication Barriers

The ability to effectively communicate is limited for some individuals with disabilities because of inappropriate communication formats or methods. **"**Communication is the foundation of much of our lives and a basic human right."[53] The communication process can be influenced by someone's ability to speak, understand, read or write. Various research has been conducted with the intent of developing effective strategies in the removal of communication barriers for people with disabilities.[54]

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[45] North Carolina Office on Disability and Health. *Partners in health care*. Retrieved on March 8, 2010, from http://www.fpg.unc.edu/~ncodh/pdfs/partners.pdf

[46] Joines, S. (2009). Enhancing Quality of Life through Universal Design. *NeuroRehabilitation. 2009; 25 (3):155-67*. Retrieved on March 8, 2010, from http://iospress.metapress.com/content/5g112p283123h141/fulltext.html

[47] Steinfeld, E. and Danford, S. (2006). *Universal Design and the ICF*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/en/downloads/New%20Presentations/ICF%20Presentation%20Notes.pdf

[48] Council of Canadians with Disabilities. (2008). *A Disability Rights Analysis of Canada's Record Regarding the Human Rights of Persons with Disabilities: A Submission by CCD to the Human Rights Council in Relation to the 2009 Periodic Review of Canada*. Retrieved on March 8, 2010, from http://www.ccdonline.ca/en/humanrights/promoting/periodic-review-2009

[49] *Ibid*

[50] Lepofsky, D., and Graham, R. *Universal Design in Legislative Drafting – How to Ensure Legislation is Barrier-Free for People with Disabilities*. Retrieved on March 8, 2010, from http://www.crvawc.ca/documents/Universal%20design%20in%20drafting%20barrier%20free%20legislation%20for%20people%20with%20disabilities.pdf

[51] *Ibid*

[52] *Ibid*

[53] Ontario Ministry of Community and Social Services. (2009). *Communication Access for People who have Communication Disabilities*: *Guidelines and Resources on Communication with People who Have Communications Disabilities*. Retrieved on March 8, 2010, from http://www.accesson.ca/documents/en/mcss/accessibility/DevelopingStandards/Communication_Access_ENG_no_ack.pdf

[54] Brathwaite, D. and Thompson, T. (ed). (2002). *Handbook of Communication and People with Disabilities: Research and Application*. Retrieved on March 8, 2010, from http://www.questia.com/read/28054019?title=Handbook%20of%20Communication%20and%20People%20with%20Disabilities%3a%20Research%20and%20Application

Individuals with communication impairments experience barriers when accessing programs and services due to the impatience of others who do not take time to adjust to the communication needs of the individual. There are augmentative communication devices that allow individuals with disabilities to communicate; however, finite financial resources limit the ability for service providers to take full advantage of these technologies.

Transportation Barriers

Inappropriate and inaccessible transportation is another barrier faced by people with disabilities when attempting to access services. The federal government of Canada conducted a review on the Canada Transportation Act in order to see what needs to be implemented for equal access to transportation for people with disabilities and the general public.[55] According to the Review Panel, "people with disabilities have traditionally had difficulty making full use of the transportation system to get to work, travel on business, visit friends and relatives, or take a vacation. Obstacles in the system have prevented these Canadians from participating fully in activities others take for granted."[56]

Canadians With Disabilities – Demographics

- In 1991 15.5% of the population – 4.2 million people – reported having a disability.
- Adults with disabilities numbered 3.53 million (16.8%).
- Those with mobility disabilities were estimated at 2.02 million (9.6%), and those using wheelchair at 124,000 (0.6%).
- Adults unable to use intercity services or having difficulties using them represented 5% of the total adult population (1.06 million people), and those experiencing difficulties using local transportation also represented about 5%.
- Individuals with limitations relating to mobility amounted to 7.2% of the adult population, and 75% of those were classified as transportation disabled.
- Among persons classified at transportation disabled, 31% had hearing limitations, 19% had sight limitations and 9% had speech limitations.
- About 40% of transportation disabled individual had disabilities relating to mental health conditions, learning disabilities, or developmental disabilities.

Source: Canada Transportation Act Review Panel

Figure 1: Canadians With Disabilities - Demographics

Inappropriate transportation leads to social exclusion which "refers to constraints that prevent people from participating adequately in society, including education, employment, public services and activities."[57] Various court cases filed in Canada have successfully informed the public about transportation barriers that are faced by Canadians with disabilities. For example, the Canadian Transportation Agency ruled that obesity is a disability, and it should be accommodated.[58]

In *Council of Canadians with Disabilities vs. Via Rail Canada Inc.*, the Supreme Court of Canada declared the following:

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[55] Canada Transportation Act Review Panel. (2001). *Vision and Balance: Report of the Canada Transportation Act Review Panel.* Retrieved on March 8, 2010, from http://www.reviewcta-examenltc.gc.ca/english/pages/final/tablee.htm

[56] *Ibid*

[57] Litman, Todd. (2003). *Social Inclusion As A Transport Planning Issue in Canada: Contribution To The FIA Foundation G7 Comparison*. Retrieved on March 8, 2010, from http://www.vtpi.org/soc_ex.pdf

[58] *McKay-Panos v. Air Canada*. Retrieved on March 8, 2010, from http://www.schenklaw.ca/resource/mackay.htm

> "that a safe, economic, efficient and adequate network of viable and effective transportation services accessible to persons with disabilities and that makes the best use of all available modes of transportation at the lowest total cost is essential to serve the transportation needs of shippers and travellers, including persons with disabilities, and to maintain the economic well-being and growth of Canada and its regions and that those objectives are most likely to be achieved when all carriers are able to compete, both within and among the various modes of transportation, under conditions ensuring that, having due regard to national policy, to the advantages of harmonized federal and provincial regulatory approaches and to legal and constitutional requirements."[59]

This court decision demanded that rail transportation be made accessible and available for people with disabilities who use wheelchairs or scooters.

"Accommodating disabled people should be seen as part of the cost of doing business in Canada,"[60] and without the effort of the federal, provincial, or municipal governments this cannot be accomplished. Without proper transportation methods, people with disabilities will continue to be excluded from society and services necessary for maintaining quality of life.

Barriers to Access Health and Medical Services

According to Health Canada, Canadians experience barriers to health care such as "availability of services, financial barriers, non-financial barriers to presentation of health care needs, and barriers to equitable treatment."[61] Access to services for health support, prevention, and medical treatments is vital for people with and without disabilities. Without proper access to health and medical services, individuals might experience an increase in health problems or develop new conditions. Without proper diagnosis, individuals are unable to maintain proper quality of life. People with disabilities require the health care system to be more receptive because of the varying needs for health promotion, prevention, and treatment.

Although medical technology and treatments have advanced, many people with disabilities still experience barriers when accessing health and medical services. Few studies have been conducted where "the findings highlight the complex nature of access barriers for people with disabilities and underscore the importance of disability literacy in the health service delivery process."[62] These studies identified barriers to health and medical services like "environmental barriers; structural barriers, related to participants' insurance plan benefits and requirements; and process barriers, related to the way that providers deliver services." As Scheer, Kroll, Neri, and Beatty describe, individuals identified barriers because of the difficulty in accessing appropriate transportation, difficulty in making timely appointments and describing symptoms, and the inability to have appropriate communications with the medical staff. [63]

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[59] *Council of Canadians with Disabilities vs. Via Rail Canada Inc.* Retrieved on March 8, 2010, from http://scc.lexum.umontreal.ca/en/2007/2007scc15/2007scc15.html

[60] Council of Canadians with Disabilities. (2008). *CCD Wins Removal of Longstanding Barrier to Mobility and Travel*. Retrieved on March 8, 2010, from http://www.ccdonline.ca/en/transportation/air/no-surcharge-extra-inflight-seat

[61] Health Canada. (2001). *Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada*. Retrieved on September 28, 2010, from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-certain-equit-acces/2001-certain-equit-acces-eng.pdf

[62] Scheer, J.; Kroll, T.; Neri, M.T.; and Beatty, P. (2003). Access barriers for persons with disabilities, *Journal of Disability Policy Studies*, 13(4): 221-230.

[63] Bachman, S. et al. (2006). *Provider Perceptions of Their Capacity to Offer Accessible Health Care for People with Disabilities*. Retrieved on March 8, 2010, from

The following section will present the literature review findings concerning barriers to health and medical services experienced by people with disabilities.

Attitudinal Barriers

When accessing health and medical services, people with disabilities experience a focus on their disabilities rather than abilities. It seems that "health care professionals are just as lost as everyone else when dealing with people with disabilities."[64]

A study conducted in Ontario probed the difference of service provision between people with disabilities and people without disabilities. "Statistics at both the national and local levels confirm that although people with disabilities have greater need for health services, including both institutional and community services, they also experience significant disadvantages in attempting to access service."[65] One of the main findings in this study was that patients with disabilities take and require more time when accessing health services – extra time that physicians do not have and do not want to allocate. In addition, since patients with disabilities require assistance during exams, many physicians refuse to take on the liability of assisting them.

Care

Accessing appropriate ongoing and preventive care has been a challenge for many people with disabilities.[66] One issue is determining how to synchronize and assure that the patient-provider relationship is continuous and without major interruptions.[67] According to Bowers et al, barriers to care "are physical, social and economic, the most significant of which include: transportation difficulties, inaccessible offices, inadequate provider knowledge, provider attitudes, and inadequate medical insurance coverage.[68] Various studies have shown that when people with disabilities do not have proper access to heath and medical services, hospitalization incidents are high and development of "secondary conditions."[69] In 2003, "fifteen percent of Canadians reported difficulty accessing routine care, and 23% reported difficulties with immediate care" according to the *Health Services Access Survey* and the *Canadian Community Health Survey*.[70] In another study, "35% to 50% of respondents who

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http://www.questia.com/read/5018547466?title=Provider%20Perceptions%20of%20Their%20Capacity%20to%20Offer%20Accessible%20Health%20Care%20for%20People%20with%20Disabilities

[64] Roush, Susan. (1986). Health Professionals as Contributors to Attitudes towards Persons with Disabilities: A Special Communication. *Physical Therapy Volume 66/November 10, October 1986*. Retrieved on March 8, 2010, from http://ptjournal.apta.org/content/66/10/1551.full.pdf

[65] McColl, M., Forster, D., Shortt, S., Hunter, D., Dorland, J., Godwin, M. and Rosser, W. (2008). Physician Experiences Providing Primary Care to People with Disabilities. *HealthCare Policy, 4(1) 2008: e129-e147*. Retrieved on March 8, 2010, from http://www.longwoods.com/content/19989

[66] Iezzoni, L., Davis, R., Soukup, J. and O'Day, B. (2003). Quality Dimensions That Most Concern People With Physical and Sensory Disabilities. *ARCH INTERN MED/VOL 163, SEP 22, 2003*. Retrieved on March 8, 2010, from http://archinte.ama-assn.org/cgi/reprint/163/17/2085

[67] Bowers, B., Esmond, S., Lutz, B. and Jacobson, N. (2003). Improving Primary Care for Persons with Disabilities: the Nature of Expertise. *Disability & Society, Vol. 18, No. 4, 2003, pp. 443–455.* Retrieved on March 8, 2010, from http://www.dhs.wisconsin.gov/wipartnership/pdf-wpp/appe.pdf

[68] *Ibid*

[69] *Ibid*

[70] Sanmartin, C. and Ross, N. (2006). Experiencing Difficulties Accessing First-Contact Health Services in Canada. *HealthCare Policy, 1(2): 103-119*. Retrieved on September 29, 2010, from http://www.longwoods.com/content/17882

met the criteria for mental health or substance abuse did not seek services" because of the perception that services will not be appropriate and that self-treatments will work better.[71]

The literature review conducted by ACCD revealed that there is a gap between the services that have been prescribed and the actual delivery of care. According to Morgan et al, the gap that currently exists in the delivery of care in Canada not only "results in significant preventable morbidity and mortality but also lengthens wait time for health care services and threatens the sustainability of our health care system."[72]

In order to eliminate barriers to adequate care, the development of a health care system which includes preventative strategies,[73] or initiatives to develop practical guidelines[74] in the delivery of care, is suggested. By incorporating best practices, health care professionals will be able to diagnose and treat patients with disabilities more effectively.

Environmental Barriers

Studies[75] show that individuals with physical disabilities experience difficulties in accessing health and medical services because they are unable to enter the doctor's office, use the necessary equipment, or access the washrooms. "About one third of people with physical disabilities feel they are experiencing access barriers to receiving appropriate primary health care."[76]

Another study[77] demonstrated that there is a difference between stated and actual accessibility at various health care services delivery sites. Services providers assume their locations are accessible to all, but this is not always the case. The difference in the perceptions of accessibility lies in the lack of appropriate knowledge or limited financial resources to upgrade offices and facilities.

Medical Equipment

For people with disabilities, accessing medical equipment represents another barrier in receiving proper health care and health-promotion services. Individuals experience lack of access due to inaccessible diagnostic, therapeutic, procedural, rehabilitation, and exercise equipment, such as examination and treatment tables and chairs, weights scales, x-ray equipment, glucometers, blood pressure cuffs, and exercise machines.[78]

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[71] Urbanoski, K., Cairney, J., Bassani, D. and Rush, B. (2008). Perceived Unmet Need for Mental Health Care for Canadians With Co-occurring Mental and Substance Use Disorders. *Psychiatric Services March 2008 Vol. 59 No. 3*. Retrieved on March 8, 2010, from http://psychservices.psychiatryonline.org/cgi/reprint/59/3/283

[72] Morgan, M., Zamora, N. and Hindmarsh, M. (2007). *An Inconvenient Truth: A Sustainable health care System Requires Chronic Disease Prevention and Management Transformation*. Retrieved on March 8, 2010, from http://www.northwestlhin.on.ca/uploadedFiles/Home_Page/Integrated_Health_Service_Plan/An%20Inconvenient%20Truth.pdf

[73] *Ibid*

[74] William F. Sullivan, John Heng, Yona Lunsky, et al. (2006). Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities. *Canadian Family Physician* 52: 1410-18. Retrieved on September 29, 2010, from http://www.cfpc.ca/cfp/2006/Nov/_pdf/vol52-nov-cme-sullivan.pdf

[75] Veltman, A., Stewart, D., Tardif, G. and Branigan, M. (2001). Health care for People with Physical Disabilities - Access Issues: Discussion. *Medscape General Medicine. 2001;3(2).*Retrieved on September 29, 2010, from http://www.medscape.com/viewarticle/408122_4

[76] *Ibid*

[77] Pritzlaff, C., Cesar, K., Tymus, T. and Fiedler, I. (2002). Perceived Versus Actual Physical Accessibility of Substance Abuse Treatment Facilities. *Top Spinal Cord Inj Rehabil* 2002;7(3):47–55. Retrieved on September 29, 2010, from http://thomasland.metapress.com/content/tv0rt8tle3j57k2l/fulltext.pdf

[78] Canadian Institute for Health Information. (2006). *Medical Imaging Technologies in Canada, 2006—Supply, Utilization and Sources of Operating Funds*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/products/mit_analysis_in_brief_e.pdf

People with disabilities face the potential of misdiagnosis and inappropriate preventative treatments if the physician does not have an accessible medical exam table or if tests are conducted with inaccessible imaging technology. Inconsistencies in policies regarding services provision to people with disabilities has allowed physicians across Canada to provide services according to their personal preferences and choices rather than according to best practices. Even laboratory development policies differ from province to province.[79]

According to Kelly Mack, "the predominance of inaccessible examination tables" have left "many wheelchair users not to have thorough medical examinations in years." Lack of accessible tables and chairs prevents people with disabilities from receiving quality health care. One of the primary reasons that many health care clinics and facilities do not have accessible equipment is because physicians fear the cost of making improvements. When purchasing new medical equipment such as exam tables and chairs, the cost for accessible and inaccessible exam tables and chairs is comparable. Mack stated that no transfer staff will be needed if a physician has an accessible exam table and the accessible chair or table will not only benefit the patient but also the physician.[80]

Individuals with mobility issues have difficulty accessing proper diagnostic tests as they are not able to transfer to and from the equipment without proper supports or transfer teams; therefore, the rate of misdiagnosis is much higher. Women with physical disabilities are less likely to receive PAP tests compared to women without disabilities.[81]

With the passing of the American with Disabilities Act in the United States, many health care institutions were obligated to purchase height-adjustable examination tables, provide staff training, and pay monetary penalties. [82] Furthermore, medical professionals were given tax credits to purchase accessible equipment. These legislatives policies and incentives assisted in creating accessible health and medical services for Americans with disabilities.[83]

In order to address these challenges, health care service providers need to incorporate accessibility into their practices and the "ability to identify the need for equipment to assure an exam or procedure can be fully conducted," and gain knowledge about what accessible equipment is and the proper usage of it.[84]

Communication Barriers

Patients with communication, intellectual or developmental impairments experience difficulties in establishing appropriate patient-doctor relationships because of the communications barriers they experience.[85] Literature reveals that health care providers feel

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[79] *Ibid*
[80] Mack, Kelly. (2005). *Accessible Medical Exam Tables: Just Ask*. Retrieved on March 8, 2010, from http://www.equalizers.org/issues/New_Mobility_Dec05.pdf
[81] *Ibid*
[82] *Ibid*.
[83] Issaacson Kailes, J. and Mac Donald, C. (2009). *Importance of Accessible Examination Tables, Chairs and Weight Scales*. Retrieved on March 8, 2010, from http://www.cdihp.org/briefs/1%20%20Brief-Exam%20Tables%20and%20Scales-FINAL%20Edition%204_4%208%2009.pdf
[84] Mudrick, N. and Yee, S. (2007). *Defining Programmatic Access to health care for People with Disabilities*. Retrieved on March 8, 2010, from http://www.dredf.org/healthcare/Healthcarepgmaccess.pdf
[85] Wullink, M., Veldhuijzen, W., Schrojenstein Lantman, H., Metsemakers, J., and Dinant, G. (2009). Doctor-Patient Communication with People with Intellectual Disability - a Qualitative Study. *BMC Family Practice* 2009, 10:82 doi:10.1186/1471-2296-10-82. Retrieved on March 8, 2010, from http://www.biomedcentral.com/content/pdf/1471-2296-10-82.pdf

more uneasy providing medical care to individuals with communication impairments than to individuals with physical disabilities.[86] These communication barriers exist because of a lack of training in communication alternatives.

In *Provider Perceptions of Their Capacity to Offer Accessible Health Care for People with Disabilities*, Bachman, Vedrani, Drainoni, Tobias, and Maisels present "preliminary data about the results of a comprehensive survey of providers regarding their perceptions of access to health care for people with a broad range of disabilities."[87] The results of this study indicated that medical professionals are "more likely to provide services to patients with chronic illness, mobility, cognitive, or psychiatric impairments than they are to serve individuals with communication limitations or visual impairments."[88] It was reported that assisting individuals with communication impairments represents a barrier for the physicians and the patients because of the inability to appropriately communicate symptoms and treatments. "Provider perceptions of access to health care suggest that individuals with disabilities do not have easy access to health-care providers, despite changes brought on by the ADA."[89]

Individuals who are Deaf or Hard of Hearing tend to experience barriers to services because of the inability to secure sign language interpreters or communication technology. These barriers are even more profound when accessing counselling services.

ACCD's literature review revealed that there are many barriers within the health care professionals' service provision, as doctors or specialist do not always have proper access to disability-related training and ongoing guidance with new available technologies.[90]

Wait times

According to Statistics Canada, 49% to 71% of individuals waiting for surgery in 2005 were affected by worry, stress, and anxiety.[91] The chart below shows that the longest waiting times are for non-emergency surgeries, followed by waiting times for specialist visits.

[86] Chew, K., Iacono, T. and Tracy, J. 2009). Overcoming Communication Barriers: Working with Patients with Intellectual Disabilities. *Australian Family Physician Vol. 30, January/February 2009*. Retrieved on March 8, 2010, from http://www.racgp.org.au/afp/200901/200901chew.pdf

[87] Bachman, S. et al. (2006). *Provider Perceptions of Their Capacity to Offer Accessible Health Care for People with Disabilities*. Retrieved on March 8, 2010, from http://www.questia.com/read/5018547466?title=Provider%20Perceptions%20of%20Their%20Capacity%20to%20Offer%20Accessible%20Health%20Care%20for%20People%20with%20Disabilities

[88] *Ibid*

[89] *Ibid*

[90] Hogg, J. (2001). Essential health care for People with Learning Disabilities: Barriers and Opportunities. *Journal of the Royal Society of Medicine 2001 July; 94(7): 333–336*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1281596/

[91] Statistics Canada. (2005). *Access to Health Care Services in Canada*. Retrieved on March 8, 2010, from http://www.statcan.gc.ca/pub/82-575-x/82-575-x2006002-eng.pdf

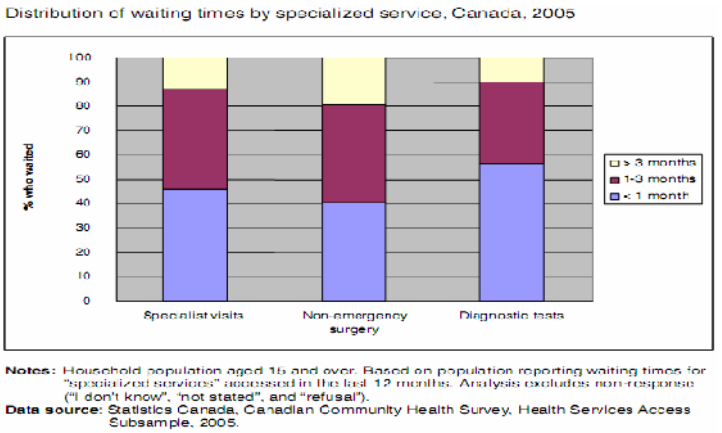

Figure 2: Distribution of waiting times by specialized services, Canada, 2005

Access to timely health services became a debated issue even at the Supreme Court of Canada during the *Chaoulli v. Quebec* case in 2005.

Governments have been attempting to tackle this issue and create standards of acceptable wait times for health services. Provinces, such as Ontario, have developed a *Wait Time Strategy*[92] with the goals of creating an effective prioritisation for surgery, improvement of patient access to services, and elimination of the development of additional symptoms.

Gender-related disparities in the access of health care services

Disability feminists have raised valuable awareness on issues experienced by women with disabilities and the struggles faced on a daily basis when accessing health and medical services; however, the literature review conducted by ACCD found that women with disabilities are not alone in their struggle for accessibility and equal treatment. The literature revealed that men with disabilities faced disadvantages as well, but there was a lack of in depth research describing the precise nature of these disadvantages.

Even though extensive research has been conducted on the experiences of women with disabilities when accessing preventative and ongoing health services, there is little research available regarding the experiences of men with disabilities who access these same services. From the evidence we found, it became evident that people with disabilities, regardless of gender, experience barriers when accessing health and medical services. As a result of these barriers, many provincial governments have started including gender as a category when developing health care strategies and delivery of health care services. [93]

Women with disabilities and access to health care

The ACCD literature review revealed that women with disabilities face many barriers and challenges when accessing preventative, ongoing, and therapeutic health services. "Women with chronic illnesses often feel labelled as malingerers, rather than offered support."[94] Women with disabilities identify barriers created by inappropriately-designed medical

[92] Walker, Sarah. (2009). *Waiting for Care: A Study of Physical and Psychological Symptoms and health care Utilization for Pain whilst Waiting for Gynaecological Surgery*. Retrieved on March 8, 2010, from http://qspace.library.queensu.ca/jspui/bitstream/1974/5247/1/Walker_Sarah_200909_MSc.pdf

[93] Prairie Women's Health Centre of Excellence. (2003). *Including Gender in Health Planning: A Guide for Regional Health Authorities*. Retrieved on March 8, 2010, from http://www.pwhce.ca/pdf/gba.pdf

[94] *Ibid*

equipment such as examination tables or chairs, inability of physicians to perform PAP tests to individuals with spinal cord injuries, lack of appropriate information regarding sexuality, and inappropriateness for various treatment options.[95] [96]

Men with disabilities and health care

Men with disabilities face gender stereotypes. They have been represented as "feminised and lacking masculine traits."[97] In his personal reflections on masculinity and disability, Tepper comments that "the social construction of masculinity begins as soon as we are born and continues for the rest of our life…from the moment the doctor pronounces 'it's a boy' males begin to establish a sense of gender identity."[98]

In many cases, living with a disability compels an individual to reflect upon perceptions of manhood and masculinity. Research suggests that men with disabilities who "measure themselves against typical masculine ideals and obsess about their inability to adequately embody them were more apt to remain emotionally immobilized."[99] This is obviously debilitating and is an issue that needs to be addressed in a positive way.

Various sources indicate that men tend to have poorer health than women. "Masculine roles and ideologies (including those of male health professionals) are most likely to play a part in discouraging men's help-seeking".[100] Men tend to consider themselves as self-reliant and in control. Seeking assistance and help regarding health-related issues is not perceived as necessary.

There is a need "to address how men's behaviour and lifestyles contribute to their immediate and long-term health needs".[101] Countries like New Zealand and Australia have conducted research in order to address the gaps in services offered to men. In addition, the governments of these two countries have been developing health policies that can address the unique needs of men and how to encourage them to access preventive and ongoing health services. [102] [103]

Lack of Health-Related Disability Policies

Our systematic literature review as well as other reviews undertaken by various organizations[104] demonstrated the lack of disability policies in Canada that can be used as a

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[95] Tudiver, S. and Hall, M. (2005). *Women and Health Care Delivery in Canada*. Retrieved on March 8, 2010, from http://www.hc-sc.gc.ca/hl-vs/pubs/women-femmes/can-usa/can-back-promo_9-eng.php

[96] Clow, B., Pederson, A. Haworth-Brockman, M. and Bernier, J. (2009). *Rising to the Challenge: Sex- and Gender-Based Analysis for Health Planning, Policy and Research in Canada*. Retrieved on March 8, 2010, from http://www.pwhce.ca/pdf/RisingToTheChallenge.pdf

[97] Meekosha, Helen. (2004). *Gender and Disability*. Retrieved on March 8, 2010, from http://www.wwda.org.au/meekoshagendis1.pdf

[98] Tepper, M. S. (1999). Letting Go of Restrictive Notions of Manhood: Male Sexuality, Disability and Chronic Illness. *Sexuality and Disability, 17*(1), 37-52.

[99] Shuttleworth, R. P. (2004). Disabled masculinity: Expanding the masculine repertoire. In B. Hutchinson & B. G. Smith (Eds.), *Gendering disability* (pp. 166-178). New Brunswick, NJ: Rutgers University Press.

[100] McKinlay, Eileen. (2005). *Men and Health: A Literature Review*. Retrieved on September 1, 2010, from http://www.phac.health.govt.nz/moh.nsf/pagescm/766/$File/mens-health-literature-review.pdf

[101] *Ibid*

[102] Smith, James. (2007). Addressing Men's Health policy Concerns in Australia: What Can be Done? *Australia and New Zealand Health Policy* 2007, 4:20 doi:10.1186/1743-8462-4-20. Retrieved on September 1, 2010, from http://www.anzhealthpolicy.com/content/pdf/1743-8462-4-20.pdf

[103] Elliot, H. and Popay, Jennie. (2000). How are Policy Makers Using Evidence? Models of Research Utilisation and Local NHS Policy Making. *J Epidemiol Community Health* 2000; 54:461–468. Retrieved on September 15, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1731692/pdf/v054p00461.pdf

[104] Spinal Cord Injury Solutions Network. (2008). *A Scoping Review of Disability Policy in Canada: Effects on Community Integration for People with Spinal Cord Injuries*. Retrieved on March 8, 2010, from http://chspr.queensu.ca/downloads/Reports/Disability%20Policy%20in%20Canada-final%20report-May09.pdf

template by the provincial or territorial governments when developing programs and services. "Disability policy in Canada has been described as conflicting, fragmented, incoherent, not user-friendly, a "hit-or-miss" affair."[105] There have been various commitments and funding opportunities for research in the development of disability-related policies and procedures; however, nothing concrete has been established by any level of government.

The only policy that ACCD's research found was *Duty to Accommodate* by the Canadian Human Rights Commission[106] and the provincial commissions. This policy was put into practice by the Ontario Human Rights Commission, which in 2008 requested that the College of Physicians and Surgeons of Ontario pass the *Physicians and the Ontario Human Rights Code* policy document. "The goal of this policy is to help physicians understand the scope of their obligations under the code and to set out the College's expectation that physicians will respect the fundamental rights of those who seek their medical services." This policy set out to clarify the basic rights and obligations of physicians toward their patients and that no discrimination should occur based "on clinical competence, moral and religious beliefs and disability."

In Section 2 of the *Physicians and the Ontario Human Rights Code* policy document, there is an explanation about expectations under the duty to accommodate statement and what undue hardship is. "When physicians become aware that existing patients or individuals who wish to become patients have a disability which may impede or limit access to medical services, the code requires physicians to take steps to accommodate the needs of these patients or individuals. The purpose in doing so is to eliminate or reduce any barriers or obstacles that disabled persons may experience." Physicians are not obligated to provide accommodation if the actions will cause undue hardship to the physician and the practice.[107]

Before the policy was finalized, the Ontario Human Rights Commission submitted a response opinion to the College of Physicians and Surgeons of Ontario with the intent of clarifying that "the **right** to accommodation rests with the person requesting the accommodation, whereas the **duty** to provide the accommodation rests with the service provider, employer or other organization." The Ontario Human Rights Commission acknowledges "the pressures that physicians face in managing their caseload and their interactions with patients in a context of doctor shortages, and an aging and increasingly diverse society. At the same time, as providers of such an essential service as health care, their efforts to ensure that their policies, practices, and decisions are free of bias and discrimination can have a significant positive impact on the lives of Ontarians."[108]

The *Physicians and the Ontario Human Rights Code* policy document is the only document that addresses accommodations in terms of the physician-patient relationship. A search within the College of Physicians and Surgeons from other provinces in Canada did not produce any policies that address this issue.

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[105] *Ibid*

[106] Canadian Human Rights Commission. *Duty to Accommodate*. Retrieved on March 10, 2010 from http://www.chrc-ccdp.ca/portal_portail/duty_obligation-en.asp .

[107] College of Physicians and Surgeons of Ontario. (2008). *Physicians and the Ontario Human Rights Code: Policy Statement #5-08.* Retrieved on March 8, 2010, from http://www.cpso.on.ca/uploadedFiles/downloads/cpsodocuments/policies/policies/human_rights.pdf

[108] Ontario Human Rights Commission. (2000). *Submission of the Ontario Human Rights Commission to the College of Physicians and Surgeons of Ontario Regarding the draft policy, "Physicians and the Ontario Human Rights Code."* Retrieved on March 8, 2010, from http://www.ohrc.on.ca/en/resources/submissions/physur?page=suben-Contents.html

Challenging the health-care system: Court Cases

There have been several court cases that have shaped how health and medical services are provided to people with disabilities. "Legal mobilization" has been implemented as an effective process in bringing change and challenging a system where certain rules do not exist.[109] According to Manfredi and Maioni, "litigation occurs when groups are systematically blocked from other avenues of political change." This is a process where disadvantaged groups seek to improve their conditions and search for justice. These types of cases cannot influence change if there is no interest in creating the ground for a transformation by the political or the judicial system.

The following cases show how litigation has been used in the courts to bring about change in various health care systems.

The Eldridge Case (Canada)

This case is in relation to accessing timely and appropriate sign language interpretative services when accessing health and medical services. The appellants, Robin Eldridge and John and Linda Warren, were born deaf, and their preferred method of communication was sign language. They were able to access these services from the Western Institute for the Deaf and Hard of Hearing – services paid for by private sources, without any contributions from the government of British Columbia.

In 1990, the Western Institute for the Deaf and Hard of Hearing decided to discontinue services because of funding cuts. The Institute tried to secure government funding, but no funding opportunities were available. The appellants contended: "the absence of interpreters impairs their ability to communicate with their doctors and other health care providers, and thus increases the risk of misdiagnosis and ineffective treatment."[110] Their argument was based on the fact that if Deaf individuals are not able to receive Sign Language services, then their citizenship rights are being eliminated.

The court stated that although hospitals are considered private entities, they still have the obligation to provide equal services. By not providing Sign language interpreters, Deaf patients will not be able to communicate with health professionals and receive appropriate care. The case was won by the appellants.

***Chaoulli v. Quebec* (Canada)**

This case involved "an individual litigant and seeked [sic] to restrict the scope of the public health care system, and challenges the very existence of publicly provided health care."[111] In 2005, George Zeliotis decided to file a complaint against the Quebec health care system because of inappropriate wait times in Quebec's public health care system. His physician, Jacques Chaoulli, wanted his home-delivered medical activities to be recognized under the health care insurance. They argued that the waiting times in the health care system are against the Canadian Charter of Rights and Freedoms and the Quebec Charter of Human Rights and Freedoms.

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[109] Manfredi, C. and Maioni, A. (2005). Litigating Innovation: Health Care Policy and the Canadian Charter of Rights and Freedoms. Retrieved June 15, 2010, from http://www.cpsa-acsp.ca/papers-2005/Manfredi.pdf

[110] Supreme Court of Canada. Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624. Retrieved June 15, 2010, from http://scc.lexum.umontreal.ca/en/1997/1997scr3-624/1997scr3-624.html

[111] Manfredi, C. and Maioni, A. (2005). *Litigating Innovation: Health Care Policy and the Canadian Charter of Rights and Freedoms*. Retrieved June 15, 2010, from http://www.cpsa-acsp.ca/papers-2005/Manfredi.pdf

"The evidence shows that, in the case of certain surgical procedures, the delays that are the necessary result of waiting lists increase the patient's risk of mortality or the risk that his or her injuries will become irreparable. The evidence also shows that many patients on non-urgent waiting lists are in pain and cannot fully enjoy any real quality of life. The right to life and to personal inviolability is therefore affected by the waiting times."[112] Individuals waiting to access health care can lead to a decrease in quality of life and sometimes death. The idea here is not to eliminate public health care but to allow individuals that are experiencing long wait times to access private health care and purchase private insurance to access these services. The government has an interest in protecting public health care but it fails to provide appropriate and timely services to its citizens. Judges agreed that the decision regarding access to private health care services has to come from within the provincial governments; however, the rights of individuals under the Charter should not be infringed by the inability to provide appropriate access.[113]

Stein v Québec Régie de l'Assurance-maladie (Canada)

Stein v. Québec Régie de l'Assurance-maladie case is about the right to access timely health services that are not available in Quebec. Mr. Stein was diagnosed at age 41 with colon cancer and had colon surgery performed. During the surgery, the doctors discovered liver lesions. Medical staff members were not able to remove them because of lack of appropriate medical equipment in the operating room. Mr. Stein was told that he will need to have surgery as soon as possible in order to prevent further spreading of the lesions. His surgery was postponed three times and after a year he was told by his doctors to have the surgery in New York. Québec Régie de l'Assurance-maladie refused to pay for his surgery because the surgery could be performed in Canada, even though Mr. Stein had been waiting for more than a year. Finally, he went to New York and had the surgery performed within eight days, which prolonged his life expectancy.

Mr. Stein was denied reimbursements, and he took his case to the Quebec Superior Court. Justice Carol Cohen held that the Régie's refusal to reimburse Stein was patently unreasonable, since it had failed to recognize that Stein had requested treatment in New York precisely because the surgery was not being performed in Montreal in a timely fashion, and because it was more than 12 weeks since the liver lesions had first been discovered. The court responded in the following way:

> "[T]o maintain that it was reasonable to make Stein continue to wait for surgery in Montreal when the danger to his well-being increased daily is irrational, unreasonable and contrary to the purposes of the Health Insurance Act, which is designed to make necessary medical treatment available to all Quebecers. (Stein 1998, paragraph 32.)"[114]

C.R. v. Alberta (Director of Child Welfare) (Canada)

This case involved the province of Alberta paying for Lovass Autism Treatment of behaviour therapy for C.R. who was diagnosed with autism and numerous behavioural problems. C.R. was enrolled in various programs, but none were helpful, and the child continued to become more aggressive and isolated. In 1995, C.R. started the Lovass Treatment for 20 hours a week

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[112] Supreme Court of Canada. Chaoulli v. Quebec (Attorney General). Retrieved June 15, 2010, from http://csc.lexum.umontreal.ca/en/2005/2005scc35/2005scc35.html

[113] *Ibid*

[114] *Stein v Québec (Régie de l'Assurance-maladie)*, [2000] QJ No 1241 (Que SC, March 28, 2000).

which was paid for by the family. C.R. exhibited major behavioural improvements. His family asked for additional hours as the child was now able to speak and recognize objects and show eye contact.

The family asked Handicapped Children's Services to pay for the additional hours and the Director of Child Welfare declined the request. The case was brought before Alberta Queen's Bench Court and the Court stated that the Director of Child Welfare erred by declaring this therapy as an education program when it assisted the child in many aspects of life. The Court saw this therapy as a great benefit to the child, and because the family had been struggling to pay for the therapy, the province should be responsible for funding 90% and the family the remaining 10%.

This case was a victory for many families in Alberta who had been trying to have the Lovass Treatment available for their children.

Auton v. British Columbia (Canada)

"The Auton case involves a well-organized social movement seeking to extend the system's coverage."[115] It challenged the authority of provincial governments to determine which services are medically necessary and included within the public health care system.

This case was about the responsibility of the provincial government to fund therapy that was not recognized by British Columbia as a necessary service and for the therapy to be provided through the province's publicly funded health care system. The intent was to have BC change its perspective toward Lovass Autism Treatment.

Even though the lower courts judged favourably towards funding the treatment, the Supreme Court of Canada reversed all previous decisions and stated that the policies of British Columbia in not funding Lovass Autism Treatment were not discriminatory. The Court stated that as long as the provinces provide necessary services, any additional new treatments are at the discretion of the provinces to fund or not to fund. Provinces are not obliged to fund new treatments if they see that current services provide all necessary supports. The Supreme Court considered this case and decided that this therapy will benefit only a few and not all citizens.

Alexander v. Choate (United States of America)

In the United States during the 1980s, many states were considering ways of how to cut back health and medical services and decrease health care spending. Many individuals with disabilities saw this as unequal treatment because cutbacks to services for able bodied and disabled individuals were considered by the states as having equivalent impact.

"Since 1985, Alexander v. Choate has stood for the proposition that financially-motivated limitations and cutbacks in state-provided health care services imposing significant negative impacts on people with disabilities are very difficult to challenge successfully under the Rehabilitation Act of 1973" (Francis and Silvers 2008). The purpose of the court case is to prove that posing a 14 day hospital limitation stay per year will have a greater negative impact on people with disabilities than on non-disabled individuals, who most of the time do

[115] Manfredi, C. and Maioni, A. (2005). *Litigating Innovation: Health Care Policy and the Canadian Charter of Rights and Freedoms*. Retrieved June 15, 2010, from http://www.cpsa-acsp.ca/papers-2005/Manfredi.pdf

not need long hospital stays. The issue was how to apply meaningful access to services for people with disabilities.[116] The Supreme Court ruled that limitations and cutbacks on health services are not discriminatory as long as they are applied equally for everyone. Critics argue that the Supreme Court failed to consider the debilitating effects of improper access to health care on people with disabilities.[117]

Disability Rights Council et al. v. Washington Hospital Center (United States of America)

Four individuals brought an action suit against the largest private hospital in Washington D.C. because of inaccessible patient rooms and inappropriate exam tables and equipment. The Plaintiffs alleged that Washington Hospital Center discriminated against the "individual plaintiffs by denying each of them the full and equal enjoyment of and access to its health care services and health care facilities, on the basis of their disabilities, in violation of Title III of the Americans with Disabilities Act."

This case is considered a landmark settlement because it addressed issues of accessibility to health care services for people with mobility and other disabilities. Washington Hospital Center, as part of the settlement, agreed to create an accessible patient room, to implement accessible medical equipment (examination tables and chairs), to develop disability related policies and procedures, and information referral and sharing. In addition, the hospital had to provide staff disability-awareness training programs.[118]

Gillespie, et al. v. Laurel Regional Hospital (United States of America)

This was a landmark case on behalf of seven Deaf individuals with the Laurel Regional Hospital in Maryland. "The individuals had alleged in their Complaint that despite their specific and repeated requests for in-person qualified Sign Language interpreter services at Laurel Hospital, these requests were denied and plaintiffs were forced to communicate through cryptic notes, lip-reading, or inadequate video interpreting, or were provided with no communication at all in critical medical situations."

One of the major issues was the inadequate video interpreting services that were provided because of the inability to have a Sign Language interpreter on site. Because the video technology used was unsuitable for their needs, patients stated that they were unable to watch the video and be assured that services were being delivered according to needs.

This case was triumphant because it conveyed a Consent Decree which required "a communication assessment of each patient, provision of appropriate auxiliary aids and services, including determining appropriate use of Laurel's new DOJ-approved VIS equipment, new policies outlining situations in which VIS is not appropriate, provision of special television equipment and telephones for deaf patients, notice to patients of their rights under the Decree, and training of staff as to its provisions."[119]

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[116] Francis, L. and Silvers, A. (2008). *Debilitating Alexander V. Choate: "Meaningful Access" to Health Care for People with Disabilities*. Retrieved on March 8, 2010, from http://www.questia.com/read/5027722057?title=Debilitating%20Alexander%20V.%20Choate%3a%20%22Meaningful%20Access%22%20to%20Health%20Care%20for%20People%20with%20Disabilities

[117] *Ibid*

[118] *Disability Rights Council et al. v. Washington Hospital Center*. Retrieved on March 8, 2010, from http://www.ada.gov/whc.htm

[119] *Gillespie, et al. v. Laurel Regional Hospital*. Retrieved on March 8, 2010, from http://thebarrierfreehealthcareinitiative.org/?page_id=16

Conclusion

These cases show various issues and challenges that are being faced by people with disabilities regarding access to health care services. Currently in the United States many issues are resolved through negotiations rather than through filing lawsuits. In Canada, the main document used to prove the need for appropriate services is the Charter of Rights and Freedoms. Litigation has been used as a way to create a change when that change does not benefit all citizens but only a few. But as Manfredi and Maioni (2005) point out "success is not a simple concept, nor is it identical to influence," and these kinds of court cases will continue until people with disabilities receive appropriate health services.[120]

Investigating barriers: Previously conducted studies

The systematic literature review produced information concerning a small number of studies previously concluded with reference to people with disabilities and access to health and medical services.

Deaf Canadians and the Canada Community Health Survey

The purpose of this survey was to correlate the health and well-being of Deaf and hard-of-hearing Canadians with Canadians who do not report a hearing impairment. The study was conducted by a cross-sectional analysis of the Canada Community Health Survey (CCHS).[121] Four percent of the Canada Community health Survey respondents stated that they have a hearing problem.[122]

This study concluded that people with hearing impairments experience lower health and well-being status compared to their counterparts without hearing problems. The study identified access to health services as a barrier because of the inability to receive proper communication, information, and diagnosis. The recommendation from this study was to institute "a national approach to communication accommodations should be the ultimate goal for any future policymaking." [123]

Aphasia Study

This study was initiated to explore the "environmental factors that hinder or support the community participation of adults with aphasia."[124] There were twenty-five interviews with adults with aphasia and ten participant observations. More than 181 barriers were recorded by 238 facilitators.

The study found that individuals with aphasia experience barriers by products and technology used. Additionally, there is inappropriate written information and lack of standardized equipment and signage. When it comes to the environment, people with aphasia experience barriers because of background noise and visual distractions. They

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[120] Manfredi, C. and Maioni, A. (2005). *Litigating Innovation: Health Care Policy and the Canadian Charter of Rights and Freedoms*. Retrieved June 15, 2010, from http://www.cpsa-acsp.ca/papers-2005/Manfredi.pdf

[121] Woodcock, K. and Pole, J. (2007). *Health profile of Deaf Canadians: Analysis of the Canada Community Health Survey. Can Fam Physician 2007;53:2140-2141.* Retrieved on March 8, 2010, from http://www.cfp.ca/cgi/reprint/53/12/2140

[122] *Ibid*

[123] *Ibid*

[124] Howe, T. and Worrall, L. (2006). *Environmental Factors and People with the Language Disorder of Aphasia*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/en/downloads/Tami%20Howe%20-%20Oral%20Health%20&%20the%20Environment.pdf

experience attitudinal barriers because those with whom they are trying to communicate are impatient and do not take the time to listen. "Health professionals as a barrier: the doctor tells the participant he wants him to have PSA blood tests and he will give him some prescriptions…After the appointment, the participant shows the researcher his lab test and prescription forms and asks what the forms are for."[125]

This study presented the findings from the interviews and proposed recommendations for changes in the health care system when working with individuals with aphasia.

Accessible Offices

The purpose of the study was to put forward recommendations of how health care professionals can make their offices physically accessible to all patients:[126]

> "General practitioners are thought to have more contact with persons with disabilities than any other profession or agency. Nevertheless, many physicians' offices are inaccessible, and there is little information readily available to Canadian physicians who wish to improve the accessibility of their offices. Persons with disabilities who require medical care are therefore deterred from seeking it by the difficulties they encounter when visiting a physician."[127]

The authors developed guidelines and recommendations of what an accessible office should look like and the types of policies that need to be implemented to accomplish the removal of barriers to physical accessibility. "Development of these guidelines was guided by a belief in the importance of this area from patient-care, ethical, societal and legal perspectives, and by input from stakeholder groups."[128]

Toronto and Area Study

The intent of the study was to explore access to primary health care for people with physical disabilities in Toronto and the surrounding area. The authors of the study examined access to health care and satisfaction of people with physical disabilities. In addition, the authors explored different elements of health care such as referrals, exams, information, and accessibility.[129]

A questionnaire was mailed to 1026 individuals with disabilities, and 201 were returned. "Among the respondents to the questionnaire, 17.4% reported having difficulty obtaining a family doctor's services and 8.0% reported having been refused medical treatment by a family doctor because of their disability. Respondents also reported difficulty in physically accessing their family doctor's office (32.3%), equipment (38.3%), and washroom (22.9%). Although 82.1% of respondents claimed they were very or somewhat satisfied with their family doctor's services, 19.4% felt they were receiving inadequate primary health care and 21.9% felt that their disability prevented them from receiving appropriate primary health care."[130] Among respondents, women with disabilities were able to access important screening tests. Health promotion services were often not offered.

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[125] *Ibid*
[126] Jones, K. and Tamari, I. (1997). Making Our Offices Universally Accessible: Guidelines for Physicians. *Can Med Assoc J 1997;156:647-56.* Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1232828/pdf/cmaj_156_5_647.pdf
[127] *Ibid*
[128] *Ibid*
[129] Veltman, Albina et al. (2001). Perceptions of Primary Health Care Services among People with Physical Disabilities. Part 1: Access Issues. *Medscape General Medicine. 2001; 3(2).* Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/408122
[130] *Ibid*

The study showed that the majority of individuals with disabilities reported experiencing various barriers when accessing health and medical services. The researchers acknowledge that the results are not compared to the general population, and the study depended on voluntary participants.[131]

Alberta Health Services Calgary Demographic Study

This study, undertaken by the Calgary Health Region within Alberta Health Services, is the only major study conducted in Alberta with the intention of exploring and identifying barriers that Albertans with disabilities experience when accessing health and medical services. "In Calgary, 15% of the population is people with disabilities. The percentage of people with a disability living in Calgary is likely higher than the provincial percentage as more services are available in urban settings (Personal Communication, Premier's Council on the Status of Persons with Disabilities, 2008)."[132] As a result of the high percentage of people with disabilities in Calgary, the Calgary Health Region needed to gather information on the barriers in order to produce solutions and establish recommendations on how to provide services to people with disabilities:[133]

> "The research found that persons with disabilities, as a group, are more likely than able-bodied counterparts to have multiple and complex health care needs, in some cases leading to proper care not being provided; perceive their health status as poor; report having unmet health care needs (including reduced rates of preventive health care services); and have lower levels of satisfaction with health care. Focus groups, however, also revealed that many persons with disabilities have had exceptionally positive experiences with individual practitioners/providers. This suggests that actions already being taken are helping to reduce barriers."[134]

The study identified three types of barriers: environmental, process, and individual.[135] Environmental barriers were identified as medical facilities and equipment, the transportation system, the provision of health information, aids and devices, and support for the activities of daily living. The study identifies process barriers such as "knowledge and experience, attitudinal influences, focus on disability, communication, sign language interpretation and coordination of care."[136]

Researchers felt that it was significant to explore individual barriers faced by people with disabilities when they attempt to communicate their personal health problems and the courage to demand health care services.[137]

This study helped the development of policies and procedures according to the needs of the population – in this instance, the population is people with disabilities. This report recommended that services for people with disabilities need to be tailored toward the elimination of the environmental, process, and individuals barriers that are experienced by people with disabilities when accessing health and medical services in Alberta.

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[131] Branigan, M. et al. (2001). Perceptions of Primary Health Care Services among Persons with Physical Disabilities. Part 2: Quality Issues. *Medscape General Medicine. 2001; 3(2)*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/408123
[132] Alberta Health Services. (2008). *Demographics: Demographic Information of Diverse Populations*. Retrieved on March 07, 2010, from http://www.calgaryhealthregion.ca/programs/diversity/demographics/demographics_of_div_pop.pdf
[133] Alberta Health Services. (2008*). Persons with Disabilities: Health Services Literature Review and Community Consultations*. Retrieved on March 07, 2010, from http://www.calgaryhealthregion.ca/programs/diversity/diversity_resources/research_publications/disabilities_report.pdf
[134] *Ibid*
[135] *Ibid*
[136] *Ibid*
[137] *Ibid*

Conclusion

These studies show the many barriers that people with disabilities face when accessing health and medical services and the need to further explore and study these barriers. Without proper understanding of the various access barriers that are experienced by people with disabilities, provincial governments will not have the awareness about the provision of proper health services. The demands on the health care system will only become greater. Understanding what is needed is a more desirable approach that can prove to be cost saving in the long run.

Summary

As Patricia Benner writes, it is crucial to develop "our moral sensibilities and possibilities in relation to our lifesaving technologies will require more than the objectified clinical vocabularies and clinical language that we presently use. Perhaps such development cannot be accomplished without some public space for weeping and for considering illness and death as human passages and not just clinical courses of disease."[138]

Creating barrier free health and medical services for persons with disabilities is a large and complex task that each government must undertake in order to create an equitable society. Environments should adhere to building codes and medical equipment should be purchased with barrier-free accessibility as a top priority. Service providers must have continuous disability-related education, and governments must step in and ensure that citizens are receiving access to appropriate preventative and ongoing health and medical services.

[138] Benner, P. (2004). Seeing the Person beyond the Disease. *American Journal of Critical Care January 2004, Volume 13, No.* . Retrieved on March 8, 2010, from http://ajcc.aacnjournals.org/cgi/reprint/13/1/75

People with Disabilities: The Impact of Numbers

Disability programs, services, and policies have their foundation in the Canadian Charter of Rights and Freedoms[139], the Canadian Human Rights Act[140], and the UN Convention on the Rights of Persons with Disabilities[141]. These legislations prevent discrimination and barriers, and seek full participation in society for persons with disabilities. They influence employment and education, and create opportunities for necessary accommodations and supports.

The following section demonstrates the demographic situation of people with disabilities in Canada.

Canadians with Disabilities

The most recent survey on people with disabilities conducted by Stats Canada was the 2006 Participation and Activity Limitation Survey (PALS). "PALS is a national survey designed to collect information on adults and children with disabilities […] whose everyday activities are limited because of a condition or health problem. Funded by Human Resources Development Canada and conducted by Statistics Canada, PALS provides essential information on the prevalence of various disabilities, the supports for persons with disabilities, their employment profile, their income and their participation in society."[142]

The results from the 2006 PALS were compared to the 2001 HALS survey and according to Stats Canada, from 2001 to 2006, "the number of persons who reported having a disability increased by three-quarters of a million people (+21.2%), reaching 4.4 million in 2006 from 3.6 million in 2001.[143] At the same time, the non-disabled population experienced lesser growth, increasing by 3.3% to reach 26.2 million people. As a result, the national disability rate increased 1.9 percentage points from its level of 12.4% in 2001 to reach 14.3% in 2006."[144]

The following table shows the population with and without disabilities, and the disability rate, by province, Canada and provinces in 2006.[145]

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[139] Canada Department of Justice. *Canadian Charter of Rights and Freedoms*. Retrieved on March 8, 2010, from http://laws.justice.gc.ca/en/charter/

[140] Canada Department of Justice. *Canadian Human Rights Act (R.S., 1985, c. H-6).* Retrieved on March 8, 2010, from http://laws.justice.gc.ca/en/H-6/index.html

[141] United Nations. *Convention on the Rights of Persons with Disabilities*. Retrieved on March 8, 2010, from http://www.un.org/disabilities/convention/conventionfull.shtml

[142] Statistics Canada. (2001). *A Profile of Disability in Canada, 2001*. Retrieved on March 8, 2010, from http://www.rhdcc.gc.ca/eng/cs/sp/sdc/pkrf/publications/research/2001-000123/89-577-XIE01001.pdf

[143] Statistics Canada. (2001). *Participation and Activity Limitation Survey*. Retrieved on March 8, 2010, from http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=imdb&adm=8&dis=2

[144] Statistics Canada. *Participation and Activity Limitation Survey 2006: Analytical Report*. Retrieved on March 8, 2010, from http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.pdf

[145] *Ibid*

Geographic name	Total Population	Persons with disabilities	Persons without disabilities	Disability rate
	number			%
Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.				
Canada (excluding territories)	30,793,810	4,408,470	26,385,340	14.3
Canada (including territories)	30,893,640	4,417,870	26,475,770	14.3
Newfoundland and Labrador	498,920	74,510	424,410	14.9
Prince Edward Island	133,750	21,750	111,990	16.3
Nova Scotia	893,790	179,100	714,690	20.0
New Brunswick	711,440	122,540	588,900	17.2
Quebec	7,396,960	768,140	6,628,830	10.4
Ontario	11,970,000	1,853,570	10,116,420	15.5
Manitoba	1,075,490	169,170	906,320	15.7
Saskatchewan	905,510	145,230	760,290	16.0
Alberta	**3,212,360**	**435,820**	**2,776,540**	**13.6**
British Columbia	3,995,600	638,640	3,356,960	16.0
Yukon	29,780	4,020	25,760	13.5
Northwest Territories	40,730	3,500	37,230	8.6
Nunavut	29,320	1,890	27,430	6.4

Figure 3: Demographic information

The highest disability rate increase in 2006 was in Nova Scotia with 20% and the lowest in Nunavut with 6.4%. The largest population of people with disabilities reside in Ontario and Quebec.

In addition, the PALS study found that disability increases with age and disability onset is higher with women, as shown on the following chart.

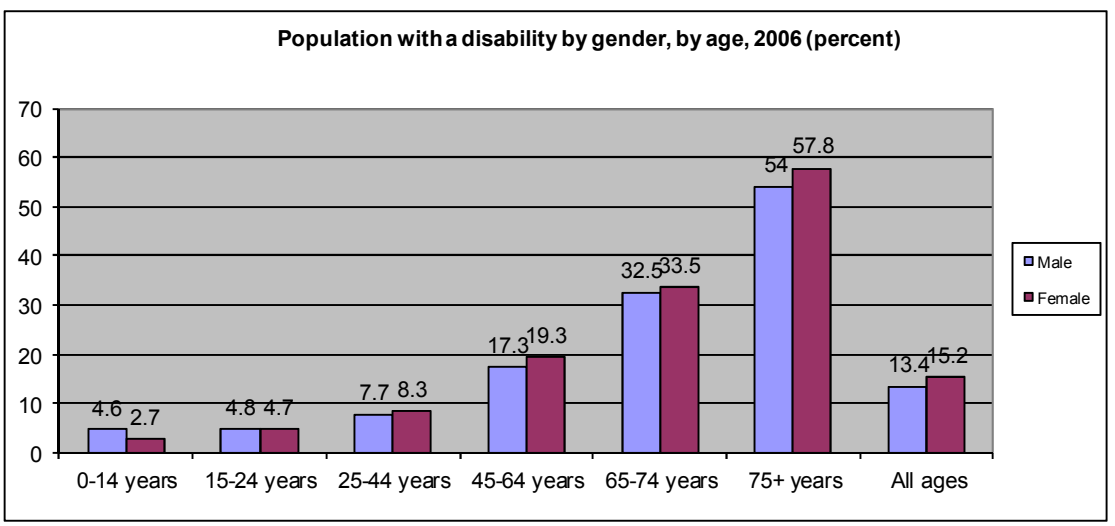

Figure 4: Population with a disability, by age, 2006 (Source: Statistic Canada, 2006)

The highest frequencies of disability types in Canada are pain (11.7%), mobility (11.5%) and agility (11.1%) impairments[146].

[146] Human Resources and Skills Development Canada. *Advancing the Inclusion of People with Disabilities: 2009 Federal Disability Report.* Retrieved on March 8, 2010, from http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2009/fdr_2009.pdf

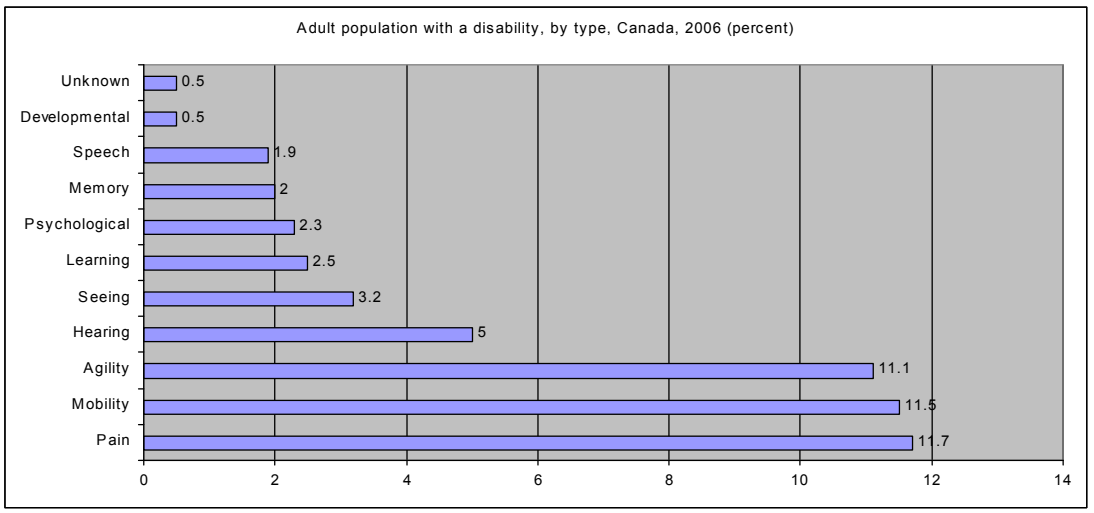

Figure 5: Adult population with a disability, by type, Canada, 2006 (Source: Statistic Canada, 2006)[147]

Comparing the Health and Activity Limitation Survey conducted in 2001 and the Participation and Activity Limitation Survey of 2006, 30% of Canadians with disabilities declared their health as *Good* which is a 1.60% drop from the survey in 2001. The chart below shows that Canadians with disabilities have stayed the same or similar during the five year span between the two surveys.

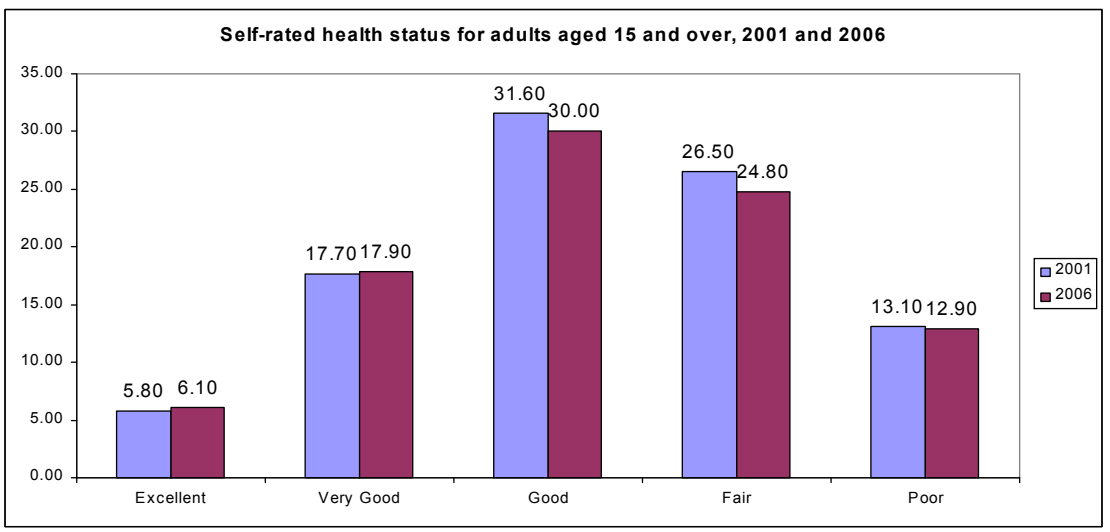

Figure 6: Self-rated health status for adults aged 15 and over, 2001 and 2006 (Source: Health and Activity Limitation Survey, 2001 and Participation and Activity Limitation Survey, 2006)

The main source of stress in 2001 for Canadians with disabilities was *Work*, while in 2005, the main source was *Health*.

[147] *Ibid*

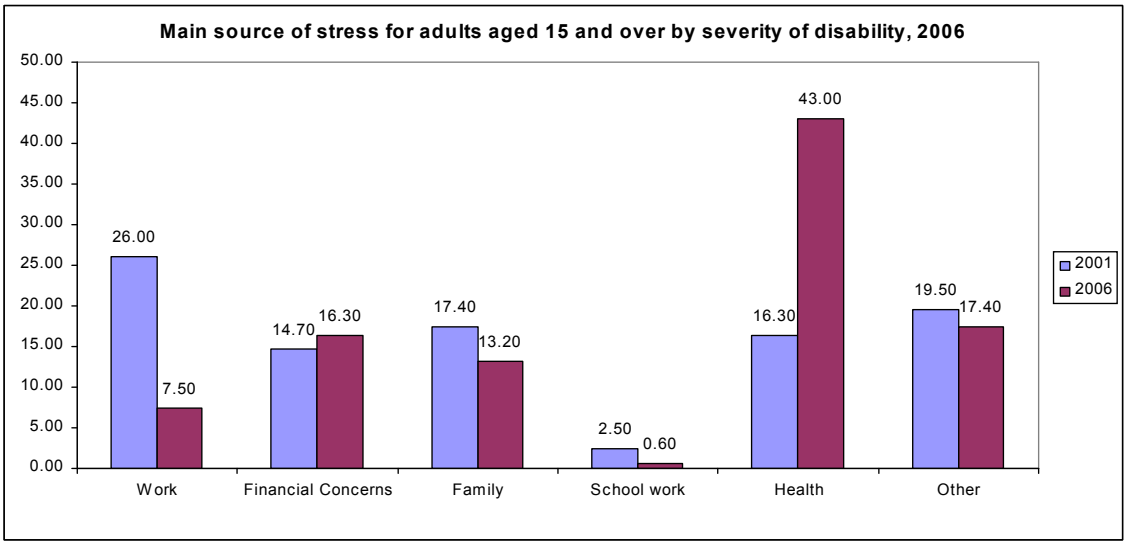

Figure 7: Main source of stress for adults aged 15 and over by severity of disability, 2006 (Source: Health and Activity Limitation Survey, 2001 and Participation and Activity Limitation Survey, 2006)

The increase of *Health* as a stress factor between 2001 and 2005 is 26.70%. This was related to Canadians with disabilities finding health services *Too Expensive*, or needed services *Not Covered by Insurance*. In the 2006 survey, 21.50% of participants did not know where they can access services.

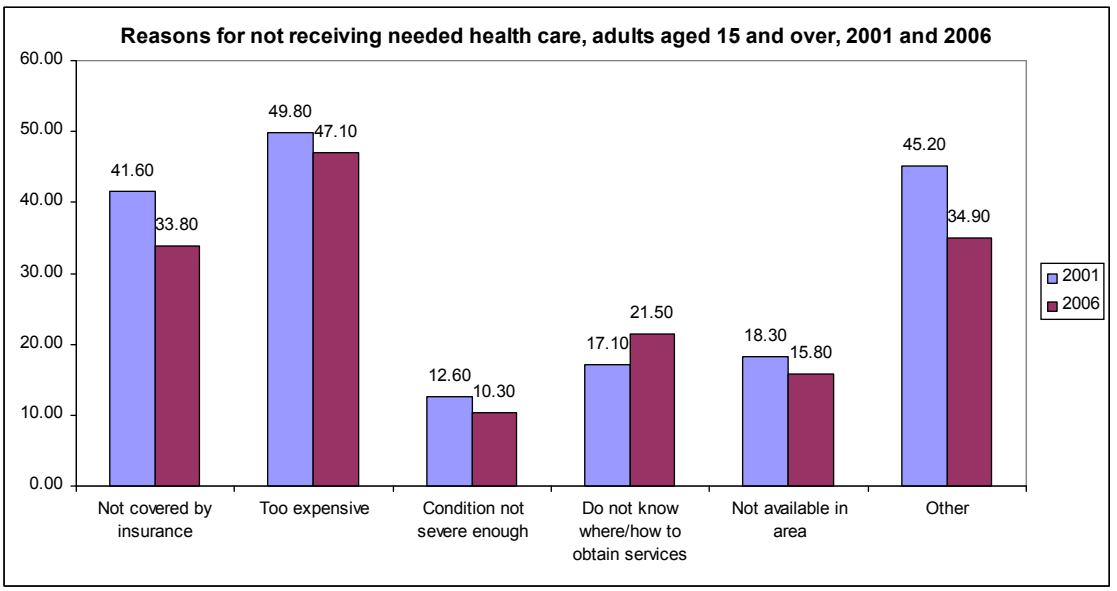

Figure 8: Reasons for not receiving needed health care, adults aged 15 and over, 2001 and 2006 (Source: Health and Activity Limitation Survey, 2001 and Participation and Activity Limitation Survey, 2006)

The number of Canadians with disabilities is expected to rise as Canada's baby boomer generation ages. According to Human Resources and Skills Development Canada, the number of Canadians with disabilities will increase, and it is projected that by 2026, there "will be over three million people with disabilities over 65 years of age – almost double the 1.6 million reported in 2001, outnumbering those with disabilities aged 25 to 64."[148]

[148] Human Resources and Skill Development Canada. (2007) *Addressing the Challenges and Opportunities of Ageing in Canada*. Retrieved on March 8, 2010, from http://www.hrsdc.gc.ca/eng/publications_resources/research/categories/population_aging_e/madrid/madride.pdf

The increase will not only affect the demographic set up of Canada, it also will transform how services are designed and delivered. "Canada is increasing its efforts to better understand the implications of the ageing population on health and long-term care needs and costs: what the future health status and health needs of the seniors' population will be and the most effective interventions to support healthy ageing."[149]

Albertans with Disabilities

According to Stats Canada the number of Albertans with disabilities increased from 354,740 in 2001 to 435,820 in 2006.[150] Fourteen percent of the population in Alberta has reported having a disability.

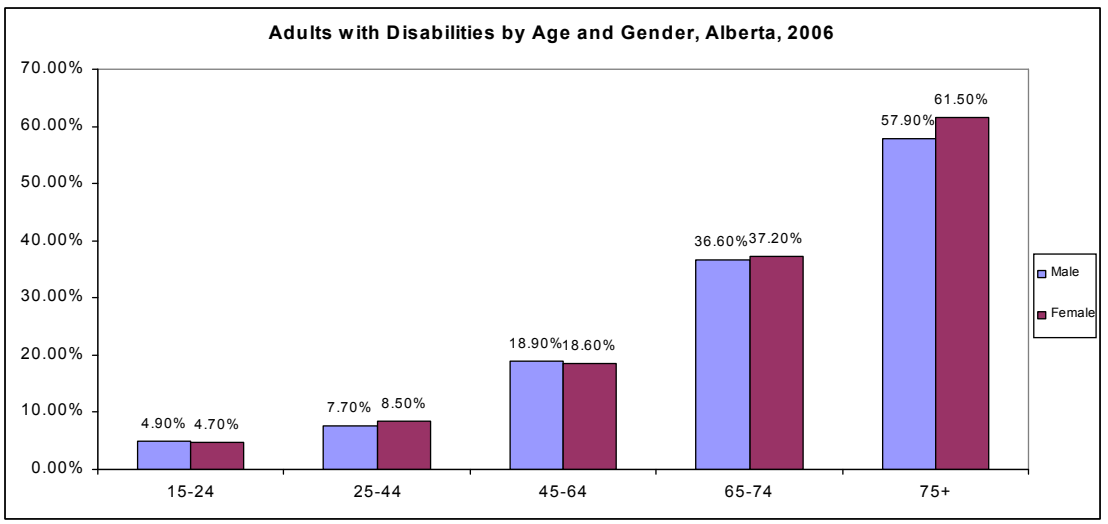

Figure 9: Adults with disabilities by age and gender, Alberta, 2006 (Source: Statistics Canada, PALS 2006)[151]

In 2006, Alberta Seniors and Community Supports issued a *Profile of Albertans with Disabilities: A Compilation of Information from National Data Sources* report with the objective of presenting demographic information on Albertans with disabilities.[152] The report states that Alberta has the third lowest disability rate among the provinces. "Over half (55.6%) of Albertans with disabilities aged 15 to 64 are active in the labour force (actively seeking employment or are employed). More than half (52%) of Albertans with disabilities aged 15 to 64 are employed. In comparison, 79.3% of Albertans aged 15 to 64 without disabilities are employed, a difference of 27%. Albertans with disabilities have the second highest employment rate across the provinces, and have the highest average total income."[153]

The most common disability impairments of Albertans are pain (68.6%), mobility (63.6%), and agility (61.30%).

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[149] *Ibid*
[150] *Ibid*
[151] Alberta Employment and Immigration. (2006). *2006 Census Analysis: Persons with Disabilities Profile*. Retrieved on March 8, 2010, from http://employment.alberta.ca/documents/LMI/LMI-LFP_profile_disabilities.pdf
[152] Alberta Seniors and Community Supports. (2006). *A Profile of Albertans with Disabilities: a Compilation of Information from National Data Sources*. Retrieved on March 8, 2010, from http://www.assembly.ab.ca/lao/library/egovdocs/2006/als/164878.pdf
[153] *Ibid*

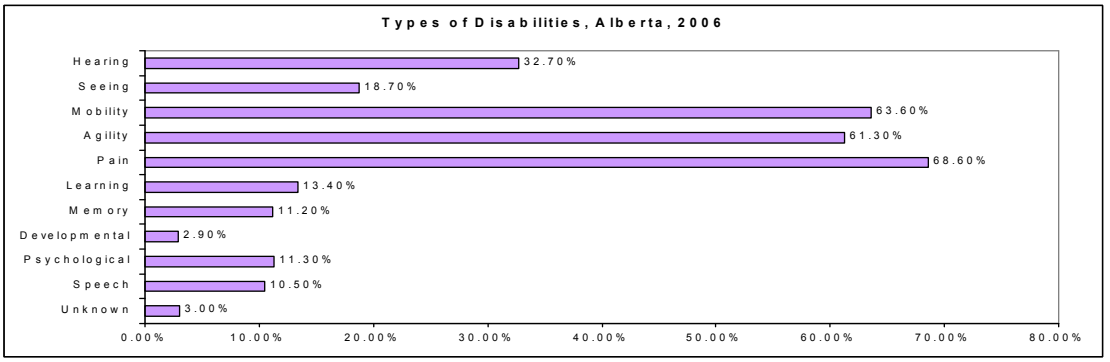

Figure 10: Types of disabilities, Alberta, 2006 (Source: Statistics Canada, PALS 2006)[154]

According to Statistics Canada, individuals between the ages of 15 to 64 make up the largest age group in Canada, as well as in Alberta.

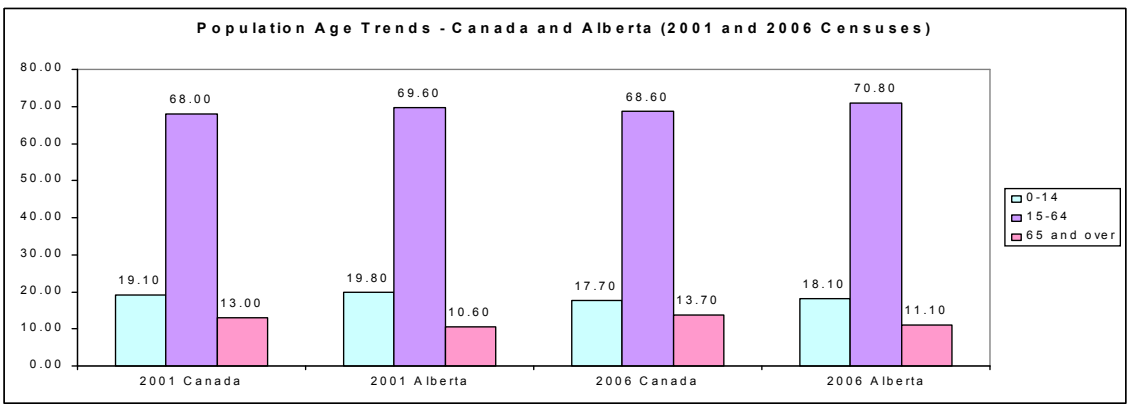

Figure 11: Population age trends – Canada and Alberta (2001 and 2006 censuses) (Source: Statistics Canada, 2007)[155]

Our literature review showed the lack of reports or demographic analysis about Albertans with disabilities. The last available demographic study was done by Alberta Health Services for the City of Calgary in 2008.[156]

Health Care in Canada

The health care system in Canada is guided by the Canada Health Act with the objective "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers,"[157] through "13 interlocking provincial and territorial health insurance plans."[158] The Canada Health Act guides the health system in the matters of "public administration, comprehensiveness, universality, portability, and accessibility."[159] Accessibility in this act is defined as monetary value and the ability for citizens to access services without being hindered by the ability to pay. "The Canada Health Act seems to be too imprecise and blunt

[154] Alberta Employment and Immigration. (2006). *2006 Census Analysis: Persons with Disabilities Profile*. Retrieved on March 8, 2010, from http://employment.alberta.ca/documents/LMI/LMI-LFP_profile_disabilities.pdf
[155] Alberta Health Services. (2009). *Demographics: Demographic Information of Diverse Populations*. Retrieved on March 8, 2010, from http://www.calgaryhealthregion.ca/programs/diversity/demographics/demographics_of_div_pop.pdf
[156] *Ibid*
[157] Government of Canada. (2010). *Canada Health Act*. Retrieved on March 8, 2010, from, http://laws.justice.gc.ca/PDF/Statute/C/C-6.pdf
[158] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[159] *Ibid*

an instrument to define and ensure comprehensiveness, accessibility, and quality throughout such a vast and diverse country."[160]

The Canada Health Act has been implemented in each province/territory through different heath care systems. The federal government has restricted the ability to implement and direct how health care systems should function and provinces/territories have a propensity to oppose conditions imposed on them. "As a result, Canada's health care system is best described as a collection of plans administered by the ten provinces and three territories, each differing from the others in some respects but similarly structured to meet the federal conditions for funding."[161]

Universal health care system is an expensive undertaking that has required much consideration on how to establish a sustainable system and deliver the care needed. As Crichton et al state:

> "the formidable commitment which the Canadian government took on when it decided to move to a publicly financed model of providing health care for all its citizens. It would seem that Canada is now moving toward greater community involvement, better understanding of the meaning of collectivist health care and ways of reforming and restructuring social organizations to increase community participation and to provide better health services to those who need those most. However, one major problem is the Canadian national deficit situation which is leading to federal withdrawal from social program support."[162]

Many of the provinces have created regional health authorities to assist with provision of services. The term privatisation has become a subject of discussion and a possible reality; however, "evidence from polls suggests that Canadians are unhappy with privatisation either by stealth or by policy."[163]

In 2004, all provinces and territories agreed on the *Ten-Year Plan to Strengthen Health Care.*[164] This was a starting point of how to improve on the following issues:

- Reducing Wait Times and Improving Access
- Strategic Health Human Resource (HHR) Action Plans
- Home Care
- Primary Care Reform
- Access to Care in the North
- National Pharmaceuticals Strategy
- Prevention, Promotion and Public Health
- Health Innovation
- Accountability and Reporting to Citizens
- Dispute Avoidance and Resolution[165]

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[160] Lewis, S., Donaldson, C., Mitton, C. and Currie, G. (2001). The Future of Health Care in Canada. *British Medical Journal* 2001;323:926–9. Retrieved on March 8, 2010, from, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121447/pdf/926.pdf

[161] Detsky, A. and Naylor, D. (2003). Canada's Health Care System – Reform Delayed. *The New England Journal of Medicine* 349;8 August 21, 2003. Retrieved on March 8, 2010, from, http://www.gdctn.org/info/HealthCare/Canada%20Reform%20Delayed-%20NEJM%202003.pdf

[162] Crichton, A., Robertson, A., Gordon, C. and Farrant, W. (1997). *Health Care: A Community Concern? Developments in the Organization of Canadian Health Services*. Retrieved on March 8, 2010, from http://www.questia.com/read/102576070?title=Health%20Care%3a%20A%20Community%20Concern%3f

[163] Lewis, S., Donaldson, C., Mitton, C. and Currie, G. (2001). The Future of Health Care in Canada. *British Medical Journal* 2001;323:926–9. Retrieved on March 8, 2010, from, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121447/pdf/926.pdf

[164] Wiget, M., Turner, D., Tonita, J., King., Nuget, Z., Alvi, R. and Barss, R. (2007). Across-Province Standardization and Comparative Analysis of Time-to-Care Intervals for Cancer. *BMC Cancer* 2007, 7:186 doi:10.1186/1471-2407-7-186. Retrieved on March 8, 2010, from, http://www.biomedcentral.com/content/pdf/1471-2407-7-186.pdf

So far, this plan has been implemented by each province/territory in a different manner and with inconsistent results. The common goals were interpreted differently and implemented with varying results.

Health Care Expenditures

According to the Canadian Institute for Health Information, in 2009, total health expenditures in Canada were $183.1 billion.

Provinces	Expenditures
Ontario	72.3 billion
Quebec	38.1 billion
British Columbia	23.3 billion
Alberta	**22 billion**
Manitoba	7.0 billion
Saskatchewan	5.9 billion
Newfound Land and Labrador	3 billion
Prince Edward Island	0.8 billion
Northwest Territories	0.4 billion
Nunavut	0.4 billion
Yukon	0.3 billion

Figure 12: Health care expenditures (Source: Canadian Institute for Health Information)[166]

The highest health expenditures in Canada are for the provision of health care in hospital settings, followed by reimbursements for medical doctors and prescription drugs.[167] While the Fraser Institute[168] foresees that the aging population will cause the health care system to collapse, Marc Lee states,

> "the population aging, in and of itself, is but a small contributor to rising cost pressures in the health care system. Based on current projections there is little to suggest a demographic time-bomb about to go off. Instead, the real challenge for financing the health care system is advances in technological possibilities, broadly defined to include pharmaceutical drugs, new surgical techniques, new diagnostic and imaging technologies, and end-of-life care."[169]

As per Canadian Institute for Health Information, one quarter of all health expenditures are for improvement and purchase of new medical technologies. "Technological change and heightened public expectations are seen as the primary sources of escalating costs." Consumers of health services are demanding the latest and most effective technology needed for diagnosis and prevention.[170]

Lack of Physicians

Lack of physicians and specialists has added to the strain on the Canadian health care system. Contributing factors to this predicament are Canadian physicians moving to other countries

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[165] Government of Canada. (2004). *A 10-Year Plan to Strengthen Health Care*. Retrieved on March 8, 2010, from, http://www.scics.gc.ca/cinfo04/800042005_e.pdf

[166] Canadian Institute for Health Information. (2009). *National Health Expenditure Trends, 1975 to 2009*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/products/National_health_expenditure_trends_1975_to_2009_en.pdf

[167] Evans, Robert. (2007). *Economic Myths and Political Realities: The Inequality Agenda and the Sustainability of Medicare*. Retrieved on September 28, 2010, from http://www.chspr.ubc.ca/files/publications/2007/chspr07-13W.pdf

[168] Skinner, B. and Roevere, M. (2009). *Paying More, Getting Less: Measuring the Sustainability of Government Health Spending in Canada*. Retrieved on September 28, 2010, from http://www.fraseramerica.org/commerce.web/product_files/PayingMoreGettingLess2009_US.pdf

[169] Marc Lee. (2007). *How Sustainable is Medicare? A Closer Look at Aging, Technology and Other Cost Drivers in the Canada's Health Care System*. Retrieved on March 8, 2010, from http://www.policyalternatives.ca/sites/default/files/uploads/publications/National_Office_Pubs/2007/How_Sustainable_is_Medicare.pdf

[170] Health Technology Assessment Task Group. *Health Technology Strategy 1.0 Final Report, 2004*. Retrieved on September 28, 2010, from http://www.cadth.ca/media/policy_forum_section/1_health_tech_strategy_1.0_nov-2004_e.pdf

and the reluctance to practice and specialize in locations where there is a great need for services. Physicians are reluctant to establish practices in areas that lack a desired standard of living.

According to the Canadian Community Health Survey, in 2008, 84% of Canadians aged 12 and older reported that they had a regular medical doctor.[171] Although, the number of physicians has doubled between 1978 (35,400) and 2008 (65,440), many Canadians are using emergency departments as a primary source of care.[172]

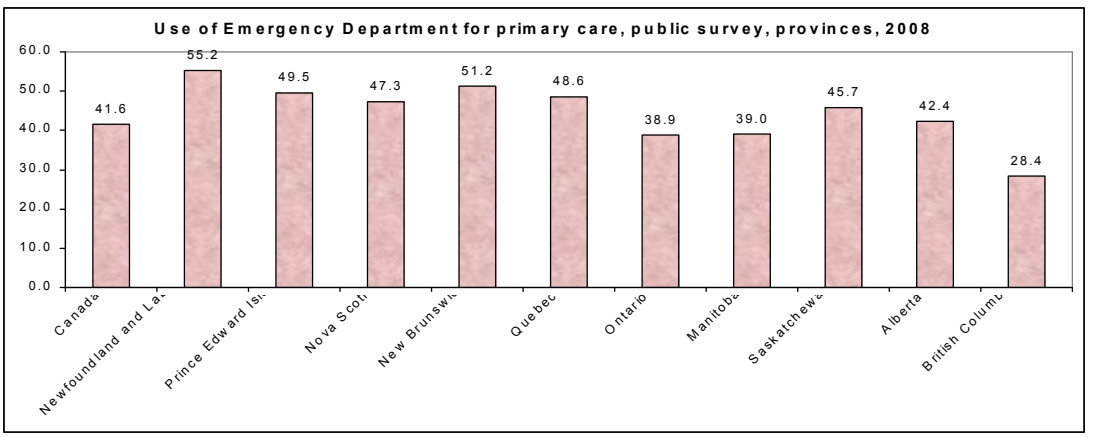

Figure 13: Use of emergency department for primary care, public survey, provinces, 2008 (Source: Commonwealth Fund, 2008)[173]

The national average for reported difficulties in accessing ongoing care is 14%. Nova Scotia has reported the lowest, while Prince Edward Island, the highest percentage of individuals that are unable to access ongoing care in 2007.

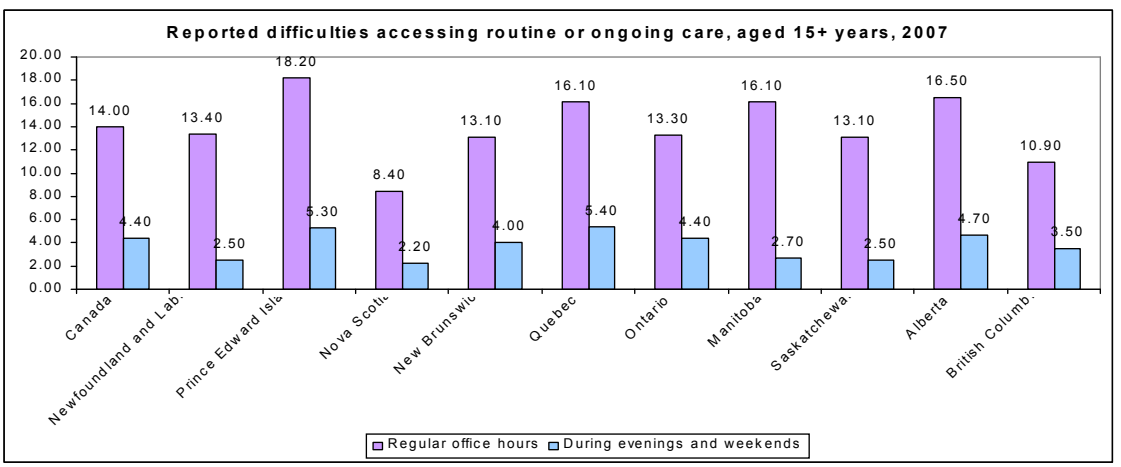

Figure 14: Reported difficulties accessing routine or ongoing care, aged 15+ years, 2007 (Source: Statistics Canada, CCHS, 2007)[174]

[171] Statistics Canada. (2009*). Canadian Community Health Survey 2008*. Retrieved on March 8, 2010, from http://www.statcan.gc.ca/daily-quotidien/090626/dq090626b-eng.htm

[172] Canadian Institute for Health Information. (2009). *Supply, Distribution and Migration of Canadian Physicians, 2008.* Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/products/SMDB_2008_e.pdf

[173] Leatherman, S. and Sutherland, K. (2010). *Quality of health care in Canada: A Chartbook*. Retrieved on September 28, 2010, from http://www.chsrf.ca/pdf/chartbook/CHARTBOOK%20Eng_June_withdate.pdf

[174] *Ibid*

The following chart shows the percentages of reported unmet health care needs in 2008.

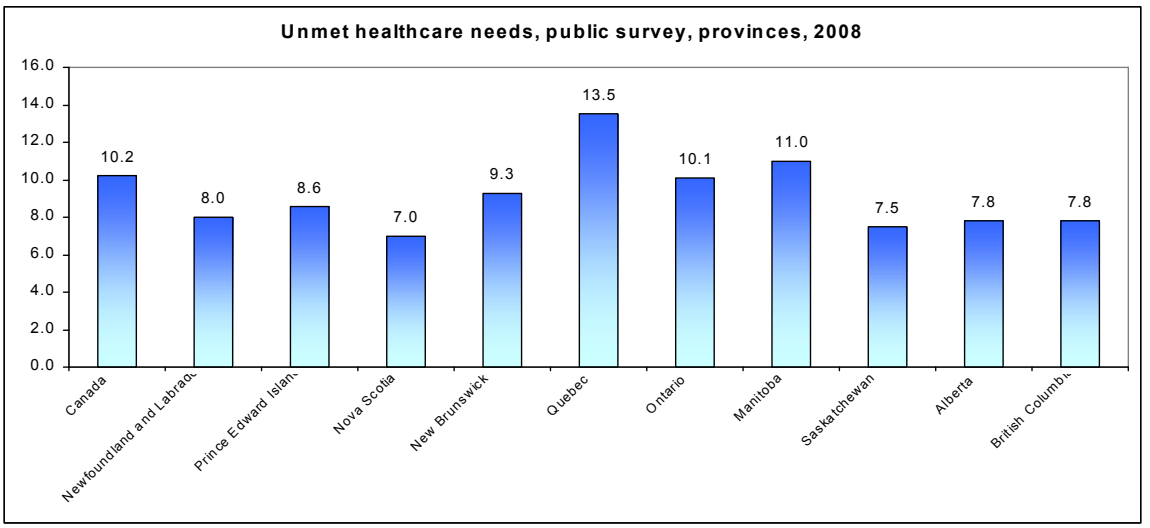

Figure 15: Unmet health care needs, public survey, provinces, 2008 (Source: CSE-PHC, 2008)[175]

These results show that the lack of physicians and specialists cause many Canadians to be unable to meet their basic health care needs and improve their quality of life.

Rural health care service delivery

Individuals living in rural areas experience challenges in accessing health and medical services in a timely and appropriate manner. These challenges do not only exist for people with disabilities, but also for the able-bodied population. It has become a more evident reality that "Canada has found it difficult to provide universal, comprehensive and equitable health care to people living in rural areas, partly because of the way in which the medical profession is organized into regional hierarchies located mainly in the larger cities, and partly because of the more advanced technology which requires complex services to be centralized."[176]

Population urban and rural, by province and territory (Canada)

	Total population	Urban	Rural	Urban	Rural
Canada	Number			% of total population	
1996	28,846,758	22,461,207	6,385,551	78	22
2001	30,007,094	23,908,211	6,098,883	80	20
2006	31,612,897	25,350,743	6,262,154	80	20

Note: The rural population from 1981 to 2006 refers to persons living outside centres with a population of 1,000 AND outside areas with 400 persons per square kilometre. Previous to 1981, the definitions differed slightly but consistently referred to populations outside centres of 1,000 populations.

*Figure 16: Population urban and rural, by province and territory (**Source:** Statistics Canada, Census of Population, 1851 to 2006. Last modified: 2009-09-22.)*

[175] *Ibid*
[176] *Ibid*

Complexity arises from the unequal distribution of physicians and specialists between urban and rural locations and the inability to have long-term physician practices in rural locations compared to the number of long-term practices in urban settings. In addition, rural physicians are expected to have a broad spectrum of knowledge and be able to respond to the diverse needs of the populations they serve.

In 2005, the Canadian Institute for Health Information produced a report titled *Geographic Distribution of Physicians in Canada: Beyond How Many and Where* in which it provided information of the current status of physicians in Canada and their distribution. As seen below, physicians are almost non existent in the northern part of Canada, and specialists are unevenly distributed across the provinces and territories.[177]

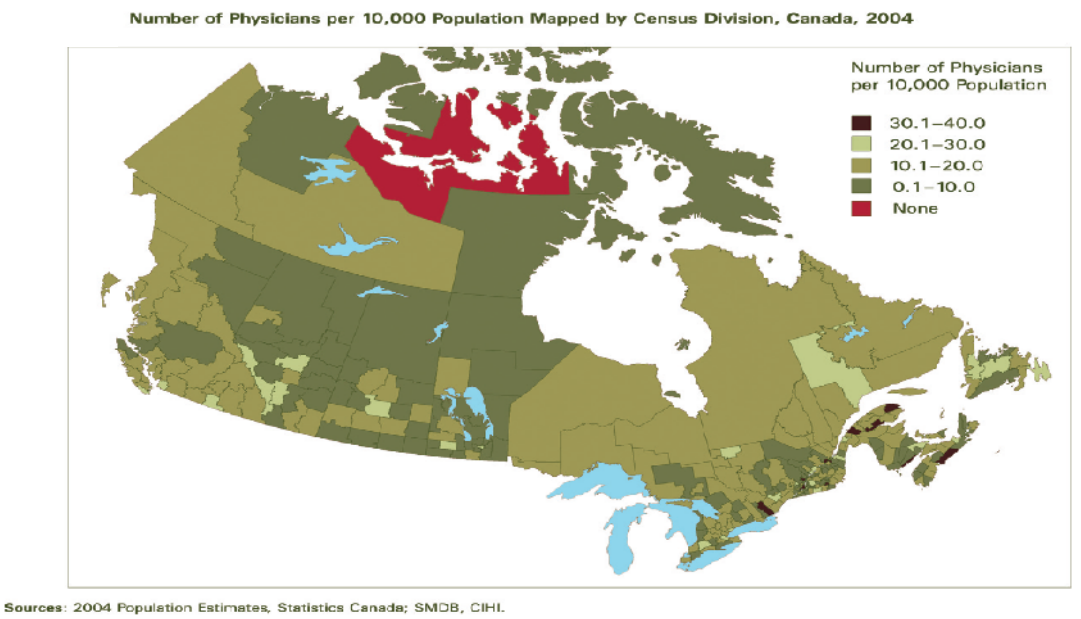

Figure 17: Number of physicians per 10,000 population mapped by census division, Canada, 2004 (Source: 2004 population estimates, Statistics Canada)

[177] Canadian Institute for Health Information. (2005). *Geographic Distribution of Physicians in Canada: Beyond How Many and Where*. Retrieved on September 1, 2010, from http://secure.cihi.ca/cihiweb/products/Geographic_Distribution_of_Physicians_FINAL_e.pdf

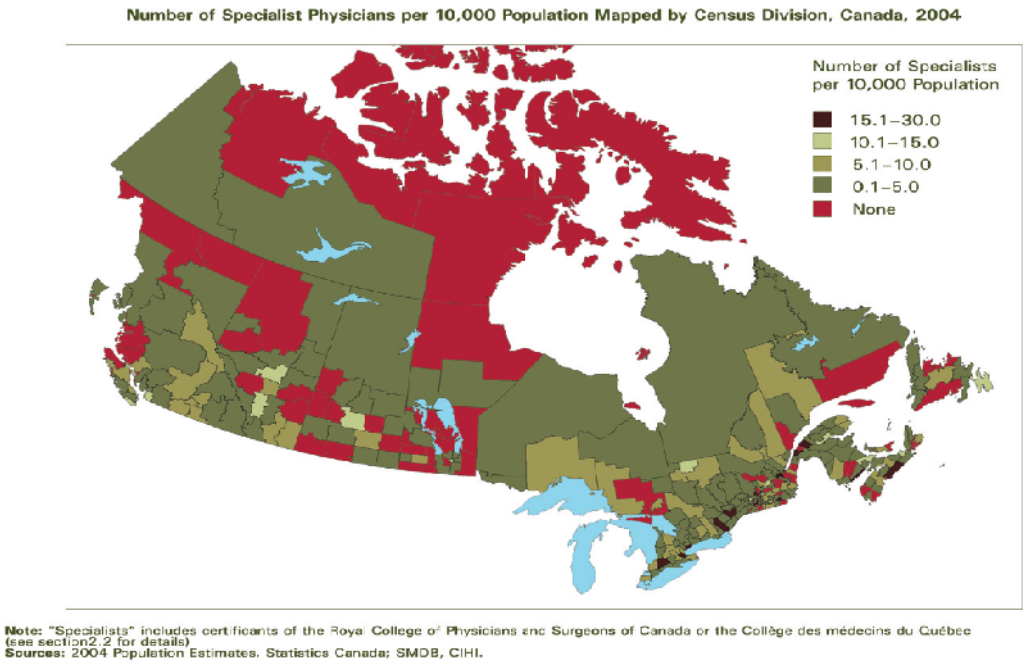

Figure 18: Number of specialist physicians per 10,000 population mapped by census division, Canada, 2004 (Source: 2004 population estimates, Statistics Canada)

The unequal distribution has affected the level of service delivery and provided challenges for policy makers during uncertain economic times. Even defining what is considered rural has added to the disparities that exist in these areas of health care delivery. "Rural Canada can be summarized as approximately one-fifth to one-quarter of the Canadian population spread over 95% of Canada's territory, there exists incredible diversity among rural regions, both demographically and economically."[178] In rural areas, patients experience higher-than-average physician turnover rate compared to turnover in urban locations.[179] [180]

A study conducted between 2002 and 2004 showed that 11% of first-year medical students that choose to establish practices in rural area "were more likely to have grown up rurally, graduated from a rural high school and have family in a rural location than others. They were more likely to be older, in a relationship, to have volunteered in a developing nation and less likely to have university-educated parents than those interested in a specialty."[181]

As Rebecca Herbert points out, "disparity in health status of rural Canadian communities is directly functional to their distance from urban centres – ultimately hindering access to available health care."[182] Countries like Germany have been working on developing polices

[178] Laurent, Stephen. (2002). *Rural Canada: Access to Health Care*. Retrieved on September 1, 2010, from http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0245-e.htm

[179] Audas, R., Ryan, A. and Vardy, D. (2009). *Where Did the Doctors Go? A Study of Retention and Migration of Provisionally Licensed International Medical Graduates Practising in Newfoundland and Labrador between 1995 and 2006*. Retrieved on September 1, 2010, from http://www.cma.ca/multimedia/staticContent/HTML/N0/l2/cjrm/vol-14/issue-1/pdf/pg21.pdf

[180] Alberta Rural Physician Action Plan. (2005). *Evaluation of the Alberta Rural Physician Action Plan: Final Report*. Retrieved on September 1, 2010, from http://www.rpap.ab.ca/pdf/2005_RPAP_Evaluation_Final_Report_9Aug2005.pdf

[181] Feldman, K., Woloschuk, W., Gowans, M., Delva, D., Brenneis, F., Wright, B., and Scott, I. (2008). The Difference between Medical Students Interested in Rural Family Medicine versus Urban Family or Specialty Medicine. *Canadian Journal of Rural Medicine 2008; 13(2): 73-9*. Retrieved on September 1, 2010, from http://www.cma.ca/index.php/ci_id/85634/la_id/1/print/true.htm

[182] Herbert, R. (2007). Canada's Health Care Challenge: Recognizing and Addressing the Health Needs of Rural Canadians. *Lethbridge Undergraduate Research Journal, 2007, Volume 2 Number 1.* Retrieved on September 1, 2010, from http://www.uleth.ca/dspace/bitstream/10133/495/1/Herbert.pdf

for rural areas that will enhance service delivery and promote innovative solutions.[183] Ontario has also created initiatives dealing with delivery of health services in rural areas, such as enhancement of the International Medical Graduates program, investment in telemedicine technology, and the establishment of the Northern Ontario School of Medicine to help keep doctors in the North.[184]

In Alberta, in 1990, a stakeholder working group was established to address the problem of rural doctor's shortages. This stakeholder working group developed a Rural Physician Action Plan. The goals were to "address primarily professional issues, but it also [encouraged] communities to enhance their capacity to address lifestyle issues," and create environments where physicians will be encouraged to live and work long-term. [185]

Population urban and rural, by province and territory (Alberta)

	Total population	Urban	Rural	Urban	Rural
	Number			% of total population	
Alta.					
1996	2,696,826	2,142,815	554,011	79	21
2001	2,974,807	2,405,160	569,647	81	19
2006	3,290,350	2,699,851	590,499	82	18

Note: The rural population for 1981 to 2006 refers to persons living outside centres with a population of 1,000 AND outside areas with 400 persons per square kilometre. Previous to 1981, the definitions differed slightly but consistently referred to populations outside centres of 1,000 population.

*Figure 19: Population urban and rural, by province and territory (Alberta) (**Source:** Statistics Canada, Census of Population, 1851 to 2006. Last modified: 2009-09-22.)*

Students and residents in medical practice are required to have a certain amount of training and residency in rural locations. In order to entice physicians to stay in rural areas, the Alberta Rural Physician Action Plan developed programs to increase retention, such as various expanded continuing medical education programs, enrichment, and the rural locum programs.[186] A similar plan was developed in Manitoba to address the challenges in rural health care.[187]

The literature review conducted by ACCD demonstrated that in today's health care system, the challenges faced by policymakers involve establishing services that will be deemed appropriate and timely by the rural population, while making sure investments do not exceed the returns.

[183] Federal Ministry of Food, Agriculture and Consumer Protection. (2008). *Innovative Service Delivery: Meeting the Challenges of Rural Regions*. Retrieved on September 1, 2010, from http://www.oecd.org/dataoecd/14/42/41063088.pdf
[184] Ontario Ministry of Municipal Affairs and Housing. (2004). *Strong Rural Communities: Working Together for Success Ontario's Rural Plan*. Retrieved on September 1, 2010, from http://www.omafra.gov.on.ca/english/rural/rural_plan/rp06heal.htm
[185] Wilson, D., Woodhead-Lyons, S. and Moores, D. (1998). Alberta's Rural Physician Action Plan: An Integrated Approach to Education, Recruitment and Retention. *Canadian Medical Association Journal February 10, 1998; 158(3).* Retrieved on September 1, 2010, from http://www.cmaj.ca/cgi/reprint/158/3/351
[186] *Ibid*
[187] Manitoba Office of Rural and Northern Health. *From Rural High School to Rural Practice*. http://www.ornh.mb.ca/docs/edu_to_sust.pdf

The Cost of Disability on the Canadian Health Care System

Marks and Teasell write that "one in 8 Canadians — a number in excess of 3.5 million people — lives with a disability. Advances in the provision of acute health care and an aging population mean that the number of people in Canada with disabilities will continue to grow. Hitherto little attention is directed toward the needs of this large patient population." New policies and initiatives have been considered with the intent of instituting timely access to care within budgets influenced and guided by cuts.[188]

The total cost of Alzheimer's disease, amyotrophic lateral sclerosis, brain tumours, cerebral palsy, epilepsy, head injury, headaches, multiple sclerosis, Parkinson's disease, spinal injuries, and stroke in Canada is estimated to be around $8.8 billion, representing 6.7% of the total attributable cost of illness in Canada in 2001.[189] Over 9% of acute care hospitalizations and 19% of patient days in acute care hospitals in Canada during the period of 2004 to 2005 were for patients with one of the above mentioned conditions as a primary or secondary diagnosis.

Marks and Teasell point out that 20% of patients receiving inpatient rehabilitation from 2005 to 2006 had one of the following conditions: head injury, multiple sclerosis, Parkinson's disease, spinal injury, or stroke.[190]

An Overview of Diseases Important in Canada[191]			
	Mortality	**Morbidity (total days stay in acute care)**	**Economic Burden**
Rank 1	Cancer	Circulatory disease	Cardiovascular disease
Rank 2	Heart disease	Cancer	Musculoskeletal disease
Rank 3	Stroke	Mental health	Cancer
Rank 4	Chronic respiratory disease	Injuries/poisoning	Injuries
Rank 5	Accidents	Digestive disease	Respiratory disease
Sources: Statistic Canada, online: CIHI, 2001; Health Canada, 1998			

Figure 20: An Overview of Diseases Important in Canada (Sources: Statistic Canada, online: CIHI, 2001; Health Canada, 1998)

[188] Marks, M. and Teasell, R. (2006). *More than Ramps: Accessible Health Care for People with Disabilities. CMAJ. 2006 August 15; 175(4): 329.* Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1534102/?tool=pubmed
[189] *Ibid*
[190] *Ibid*
[191] Leatherman, S. and Sutherland, K. (2010). *Quality of health care in Canada: A Chartbook*. Retrieved on September 28, 2010, from http://www.chsrf.ca/pdf/chartbook/CHARTBOOK%20Eng_June_withdate.pdf

Healthcare in the Provinces and Territories

The following section outlines the health care system and some current initiatives in the ten provinces and three territories in Canada.

Healthcare in Alberta

The health care system in Alberta is governed by the Alberta Health Care Act, which states that "the Government of Alberta is committed to the preservation of the principles of universality, comprehensiveness, accessibility, portability and public administration, as described in the *Canada Health Act* (Canada), as the foundation of the health system in Alberta."[192] In addition to the Alberta Health Care Act, there are approximately thirty separate pieces of legislation that guide the health system in Alberta.[193] All these legislations and regulations lead to enormous complexity for patients who access the system. In 2008, the nine regional health authorities amalgamated into one corporate organization – Alberta Health Services.

According to the Government of Alberta, policymakers are faced with developing policies for an aging population that is estimated to be 20% age 65 and over by 2031. In addition, the province has experienced increased economic costs for prevention, diagnosis, and treatment of chronic diseases. Alberta has one of the highest rates of preventable injuries and illnesses, and the need for new technologies has added to overall health care costs. Alberta is also faced with a shortage of skilled health care workers.[194] The challenge faced is how to "satisfy the needs of the public today, without compromising the needs of future generations."[195]

The vision of Alberta Health and Wellness is "healthy Albertans in a Healthy Alberta,"[196] and the challenge is how to establish sustainability when the cost "every hour is $1.7 million to maintain and improve Alberta's health care system."[197] Alberta Health Services has been allocated a $9.0 billion budget to deliver necessary services to Albertans.[198] According to the health care budget, "$3.3 billion (22.36%) has been allocated for physician compensation and development including funding for physician compensation, primary care networks, and physician office computerization."[199]

In order to build an effective health care system, the government is developing plans on how to maintain sustainability. According to Alberta Health and Wellness, "a sustainable health system is one that is accountable, operates efficiently, is cost-effective and is able to balance patients' needs with limited financial resources."[200] In addition, the system must be accountable – "measuring results, assuring Albertans an enhanced quality of services, and

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[192] The Government of Alberta. (2000*). Health Care Protection Act*. Retrieved on March 8, 2010, from http://www.qp.alberta.ca/574.cfm?page=H01.cfm&leg_type=Acts&isbncln=9780779724987

[193] Alberta Health and Wellness. (2010). *A Foundation for Alberta's Health System: Report of the Minister's Advisory Committee on Health*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/MACH-Final-Report-2010-01-20.pdf

[194] *Ibid*

[195] Di Matteo, L. and Di Matteo, R. (2009). The Fiscal Sustainability of Alberta's Public Health Care System. Retrieved on September 28, 2010, from http://policyschool.ucalgary.ca/files/publicpolicy/diMatteo%20ONLINE%20(Apr%2009).pdf

[196] Alberta Health and Wellness. (2010). *Annual Report 2009-2010*. http://www.health.alberta.ca/documents/Annual-Report-10.pdf

[197] Alberta Health and Wellness. (2010). *Health Coverage and Funding Quick Facts 2010*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/newsroom/funding-quick-facts.html

[198] *Ibid*

[199] *Ibid*

[200] Alberta Health and Wellness. (2010). *Annual Report 2009-2010*. http://www.health.alberta.ca/documents/Annual-Report-10.pdf

evaluating effective programs in the interests of continuous service improvement and enhanced health system outcomes."[201]

In 2008, the Government of Alberta developed a *Vision 2020* Plan, to address many of the challenges that the health system is facing and to assure that the system will remain responsive to the needs of the patient. "Vision 2020 sets the course for a health system that is first and foremost geared toward the needs of the patient."[202] The report states that "Albertans want and deserve an excellent health care system."[203] The government wants "to offer seniors and persons with disabilities more options for quality accommodations that suit their lifestyles and service needs."[204]

There is the ongoing discussion of how to establish a new legislative framework for the health care system in Alberta that will be patient-care centered. Alberta has been the leader in health care improvement by establishing and maintaining a 24-hour telephone health advice service and Canada's first electronic heath record system. The province has also been a leader in establishing multi-disciplinary health care teams in the provision of care. The Government has invested in the homecare system with the intent of keeping Albertans in their homes as long as possible.[205]

In addition, Alberta Health and Wellness has begun developing new and innovative service delivery methods such as telemental health, expansion of provider roles, enhancement of education and training, Rural Workforce Strategy implementation, virtual campus, and flexibility for change.[206] In 2007, Alberta created the Health Workforce Action Plan 2007-2016, to tackle the problem of how to address the shortage of health care professionals.[207]

Even though there are many innovations and changes in Alberta's health care system, there are still many barriers that exist in access to services by people with disabilities. According to the Alberta Human Rights Act, no person shall deny or discriminate "any person or class of persons any goods, services, accommodation or facilities that are customarily available to the public."[208]

The most contentious issues are duty to accommodate and undue hardship:

> "Accommodation means making changes to certain rules, standards, policies, workplace cultures and physical environments to ensure that they don't have a negative effect on a person because of the person's mental or physical disability, religion, gender or any other protected ground." Undue hardship occurs if accommodation would create onerous conditions for an employer or service provider, for example, intolerable financial costs or serious disruption to business."[209]

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[201] *Ibid*
[202] Alberta Health and Wellness. (2008). *Vision 2020: The Future of Health Care in Alberta.* Retrieved on March 07, 2010, from http://www.health.alberta.ca/documents/Vision-2020-Phase-1-2008.pdf
[203] *Ibid*
[204] Alberta Health Services. (2009). *Strategic Direction 2009-2010: Defining Our Focus/Measuring Our Progress*. Retrieved on March 07, 2010, from http://www.albertahealthservices.ca/files/org-strategic-direction.pdf
[205] Alberta Health and Wellness. (2010). *A Foundation for Alberta's Health System: Report of the Minister's Advisory Committee on Health*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/MACH-Final-Report-2010-01-20.pdf
[206] *Ibid*
[207] Alberta Health and Wellness. (2006). *Alberta Progress on the 10-Year Plan to Strengthen Health Care* . Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/Strengthen-Health-Care-Progress-2007.pdf
[208] Alberta Human Rights Commission. *Alberta Human Rights Act.* Retrieved on March 07, 2010, from http://www.albertahumanrights.ab.ca/services/medical/faqs.asp
[209] Alberta Human Rights Commission. *Web Site*. http://www.albertahumanrights.ab.ca/Bull_DutytoAccom_web.pdf

From this a question arises: how can services be provided to patients while at the same time remaining profitable? Currently, the Government of Alberta is reviewing the various health care legislations that are in effect to try to establish a system where the patient will be a contributing partner.[210]

In December 2010, the Health Quality Council of Alberta issued *Satisfaction and Experience with Health Care Services: A Survey of Albertans 2010*.[211] According to the survey, 48% of Albertans stated that it is easy to access health care services in the province. From the surveyed Albertans, the most common reason why people do not have a family doctor was because "personal family doctor not taking new patients, family doctor left/retired, and people feeling they do not need one."[212] Individuals who do not have a family doctor access walk-in clinics (56%) and emergency departments (7%) for health services.

Coordination of care still remains a challenge. According to Figure 21, 52% of surveyed Albertans expressed that the coordination of care is *good, fair or poor*.

	2010 (%)	2008 (%)	2006 (%)	2004 (%)	2003 (%)
Excellent or very good	48	49	46	48	48
Good, fair or poor	52	51	54	52	52

Figure 21: Coordination of Care Satisfaction, Health Quality Council of Alberta Survey Satisfaction 2010.[213]

The following figures show some of the findings from the Health Quality Council of Alberta Survey Satisfaction 2010.

[210] Alberta Health and Wellness. (2010). *Putting People First: Recommendations for an Alberta Health Act*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/Alberta-Health-Act-Report-2010.pdf
[211] Health Quality Council of Alberta. (2010). *Satisfaction and Experience with Health Care Services: A Survey of Albertans 2010*. Retrieved on December 26, 2010, from http://www.hqca.ca/assets/pdf/Surveys/HQCA_SE_Technical_Report_2010.pdf
[212] *Ibid*
[213] *Ibid*

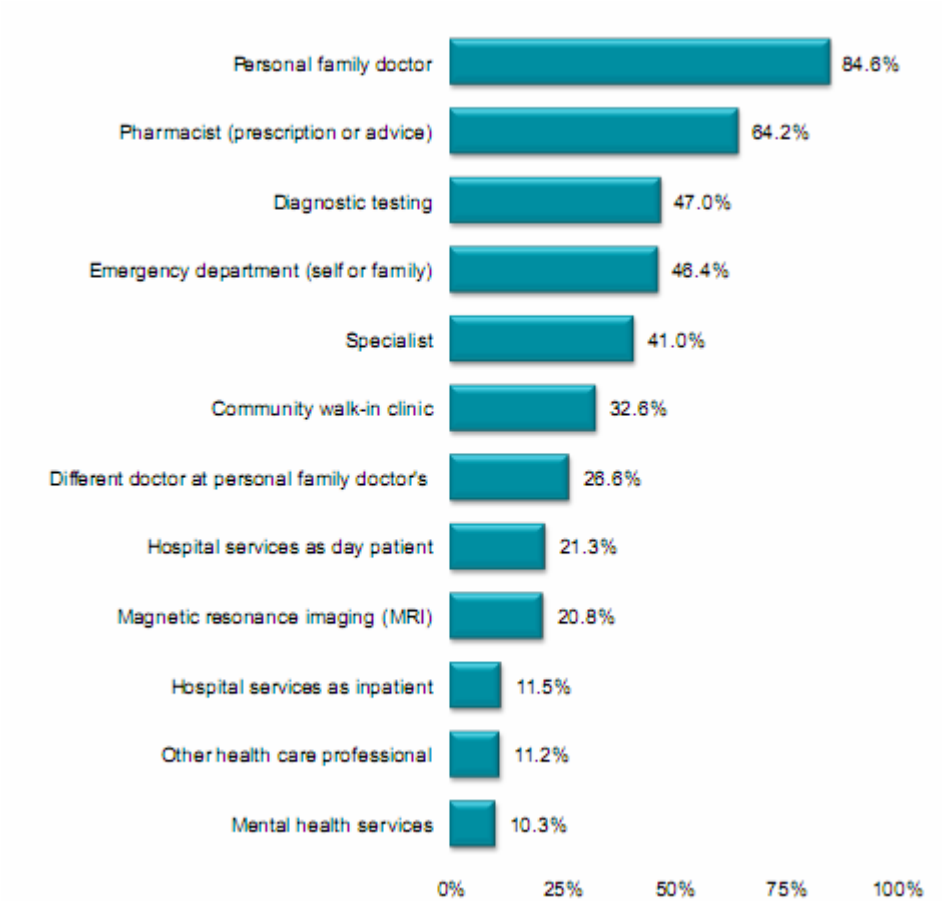

Figure 22: Proportion of Albertans (18+) receiving various health services within the past 12 months, Health Quality Council of Alberta Survey Satisfaction 2010.[214]

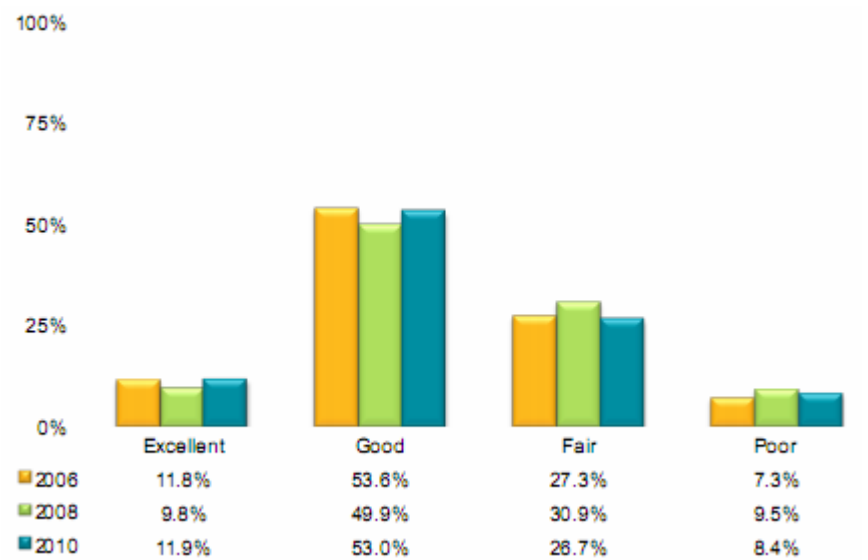

Figure 23: Perceived Quality of Health Care Services Overall, in Alberta, by year of survey, Health Quality Council of Alberta Survey Satisfaction 2010.[215]

[214] *Ibid*
[215] *Ibid*

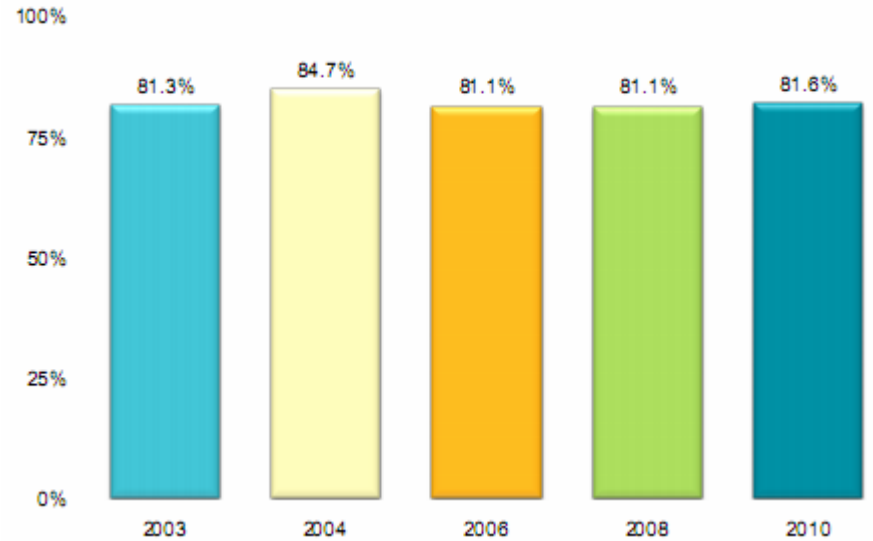

Figure 24: Percent of respondents who currently have a personal family doctor in Alberta, by year of survey, Health Quality Council of Alberta Survey Satisfaction 2010.[216]

The results from the survey show that Albertans are generally satisfied with the received health care; however, there are still areas, such as coordination of care, that need to be improved.

Healthcare in Newfoundland and Labrador

Healthcare services in Newfoundland and Labrador are delivered through the Department of Health and Community Services and four regional health authorities. "They focus on the full continuum of care including health promotion and protection, public health, community services, acute and long-term care services."[217] The vision of the Department of Health and Community Services is "for individuals, families and communities to achieve optimal health and well-being."[218]

Newfoundland and Labrador spent $2.53 billion during the 2009-2010 fiscal year, and 74.8% was spent on the health authorities and related services, 13.7% for physician services, 5.2% for the medical and drug subsidy program, 3.7% for capital, and 2.6% for other expenses.[219] The Department outlined the following strategic goals:

- Improve population health;
- Strengthen public health capacity;
- Improved accessibility to priority services; and,
- Improved accountability and stability in the delivery of health and community services within available resources.[220]

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[216] *Ibid*
[217] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[218] Department of Health and Community Services (Newfoundland and Labrador). (2011). Annual Performance Report 2009-2010. Retrieved on October 09, 2010, from, http://www.health.gov.nl.ca/health/publications/2009_2010_DHCS_Annual_Report_Tabled_Final.pdf
[219] *Ibid*
[220] *Ibid*

In the *Annual Performance Report 2009-2010*, the Department acknowledged there are many challenges that will need continuous improvement such as cancer care, rural health services, mental health and addictions, workforce planning, and pandemic planning.[221]

Healthcare in Prince Edward Island

The Department of Health and Wellness has the responsibility of delivery of necessary health and medical services in this province. The vision is:

> "Care will be delivered through a single, integrated system of care, one grounded in evidence-based decision making and focused on improving health, enhancing access and refocusing the emphasis of the care delivery system on primary health care and services that can appropriately and safely be provided locally. The system is more focused on meeting needs in the most appropriate setting, by the most appropriate provider and in the most cost effective manner."[222]

For the fiscal year 2007-2008, the Department of Health and Wellness spent $376.8 million on the delivery of health and medical services in Prince Edward Island.

The Department continues with the development of various initiatives such as "several acute and chronic conditions including cancer, heart attack, stroke, diabetes, arthritis and asthma."[223] Prevention and health enhancement are important strategic goals for this province.

Strengthening physician service-delivery remains a priority for the Department of Health and Wellness of Prince Edward Island. According to Health Canada, there is approximately 4,500 health care staff that provide services.[224] In 2007, the Department and the Medical Society of Prince Edward Island negotiated a Master Agreement with the intent of providing appropriate health services and "to establish a Tariff of Fees or other system of payment for health services."[225] As an incentive, each physician that accepts a new patient will receive $150 per new patient.[226]

Healthcare in Nova Scotia

In Nova Scotia, the Department of Health, through nine District Health Authorities and the thirty-seven Community Health Boards, delivers medical services necessary for maintaining and improving the health of its residents. "The Department of Health is responsible for setting the strategic direction and standards for health services; ensuring availability of quality health care; monitoring, evaluating and reporting on performance and outcomes; and funding health services." In addition, the Department of Health is "directly responsible for physician and pharmaceutical services, emergency health, continuing care, and many other insured and publicly funded health programs and services."[227]

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[221] *Ibid*
[222] Department of Health and Wellness Prince Edward Island. *Web Site*. Retrieved on October 8, 2010, from, http://www.gov.pe.ca/health/index.php3?number=1025090&lang=E
[223] Prince Edward Island Department of Health. (2008). *Department of Health Annual Report 2007-2008*. Retrieved on October 8, 2010, from, http://www.gov.pe.ca/photos/original/doh.pdf
[224] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[225] The Government of Prince Edward Island. (2007). *Master Agreement between the Medical Society of Prince Edward Island and the Government of Prince Edward Island: April 1, 2007-March 31, 2010*. Retrieved on October 8, 2010, from, http://www.gov.pe.ca/photos/original/doh_masteragree.pdf
[226] *Ibid*
[227] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf

The vision of the Department of Health is "generations of Nova Scotians Living Well." [228] Expenditures for the delivery of health services in 2009-2010 were $3,369,000. Strategic goals for 2009-2010 were to improve access to care and reduce wait times for surgeries. Goals have also been to improve emergency medical departments, reduce paperwork required by physicians, and enhance access to necessary mental health services.[229]

Nova Scotia has been experiencing high health costs because of the increase of the aging population compared to other provinces, the second highest rate of cancer, a high rate of diabetes, and the highest increase of reported mental health illnesses.[230]

Healthcare in New Brunswick

The vision for health care in New Brunswick is "a single, integrated provincial health care system that is patient-focused and community-based, providing health services in the official language of choice at a cost New Brunswickers can afford."[231] Health services in New Brunswick are delivered through two Regional Health Authorities. In 2008, a new provincial plan *Advancing Health Care by Putting Patients First* was introduced. The intent of this plan is to establish policies and practices that will enhance health services and implement innovation. [232]

In the 2008-2009 Annual Report, the Department of Health addressed the following core business areas:

- Protection of those most at risk;
- Prevention/education/awareness; and,
- Provision of care.[233]

The budget for health expenditures in New Brunswick is $2,247,100 for the 2008-2009 fiscal year. The largest expenditures (58.2%) are for hospital services. [234] According to Health Canada, as of 2009, there are 1,500 physicians practicing in New Brunswick.[235]

Healthcare in Quebec

The Quebec Department of Health and Social Services (the ministère de la Santé et des Services sociaux) is responsible for delivery of health services in the province. The mission of the ministry is to "maintain, improve, and restore the health and well-being of Quebecers by providing access to a set of integrated and high-quality health services and social services,

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[228] Nova Scotia Department of Health. (2009). *Annual Accountability Report for the Fiscal Year 2009-2010*. Retrieved on October 8, 2010, from, http://www.gov.ns.ca/health/reports/pubs/DOH_Accountability_2009_10.pdf
[229] Nova Scotia Department of Health. (2010). *2010-2011 Statement of Mandate*. Retrieved on October 8, 2010, from, http://www.gov.ns.ca/health/reports/pubs/DOH_Statement_of_Mandate_2010_2011.pdf
[230] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[231] New Brunswick Health and Wellness. (2004). *Healthy Futures: Securing New Brunswick's Health Care System – The Provincial Health Plan 2004-2008*. Retrieved on October 8, 2010, from, http://www.gnb.ca/0051/pdf/healthplan-2004-2008_e.pdf
[232] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[233] New Brunswick Department of Health. (2009). *2008-2009 Annual Report*. Retrieved on October 8, 2010, from, http://www.gnb.ca/0051/pub/pdf/6698ef.pdf
[234] *Ibid*
[235] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf

thereby contributing to the social and economic development of Québec."[236] All persons who reside or stay in Quebec must be registered with the Régie de l'assurance maladie du Québec to be eligible for coverage under the province's health insurance plan.[237] Health care expenditures for the 2007-2008 fiscal year were $23.8 billion, and 60% was allocated toward the support of various institutions.[238]

Healthcare in Ontario

According to Health Canada, "Ontario has one of the largest and most complex publicly funded health care systems in the world. Administered by the province's Ministry of Health and Long-Term Care (MOHLTC), Ontario's health care system was supported by over $40 billion (including capital) in spending for 2008–2009."[239] Local health services are delivered through fourteen Local Health Integration Networks.

The vision of the Ministry of Health and Long-Term Care is "to establish a patient-focused, results-driven, integrated and sustainable publicly funded health system."[240] Ontario's Ministry of Health and Long-Term Care is the only health ministry in Canada that has removal of access barriers to health and medical services as part of its mandate:

> "The Accessibility for Ontarians with Disabilities Act, 2005 sets out the roadmap to make Ontario accessible by 2025. Under this act, accessibility standards are being developed and implemented to break down barriers in key areas of everyday life. These standards will increase accessibility for people with disabilities in the areas of customer service, information and communications, employment, transportation and the built environment.
>
> The Government of Ontario is preparing to lead the way towards an accessible province, beginning in January 2010 when the first standard — for customer service — comes into force."[241]

According to the province's *Accessibility Plan for 2009-2010*, the Ministry will be focusing on ensuring that persons with disabilities do not experience barriers when accessing health and medical services. The ministry has committed "to [providing] accessibility training for all staff to ensure they are trained, as appropriate, on policies, practices and procedures that affect the way goods and services are provided to persons with disabilities." In addition, communication methods and materials will be provided in alternative forms and methods.[242] The Ministry has taken on the responsibility of developing a health care system that will be barrier free for all Ontarians.

Since the passage of the Ontarians with Disabilities Act in 2001, the Trillium Health Centre in Ontario has been committed to the "ongoing process of improving access to all of its facilities, programs, policies and services." The Centre "will conduct an ongoing review of both physical and attitudinal barriers to remove and prevent such barriers." According to the

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[236] The Ministère de la Santé et des Services sociaux. (2006). *Annual Management Report 2005-2006.* Retrieved on October 8, 2010, from, http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-102-01.pdf
[237] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[238] The Ministère de la Santé et des Services sociaux. *Web Site*. Retrieved on October 8, 2010, from, http://www.msss.gouv.qc.ca/sujets/organisation/ssss_enbref/index.php?repartition_budgetaire_en
[239] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[240] Ontario Ministry of Health and Long-Term Care. *Web Site*. Retrieved on October 8, 2010, from, http://www.health.gov.on.ca/en/ministry/default.aspx
[241] Ontario Ministry of Health and Long-Term Care. (2009). *2009-2010 Accessibility Plan*. Retrieved on October 8, 2010, from, http://www.health.gov.on.ca/en/public/publications/aplans/aplan10/aplan10.pdf
[242] *Ibid*

centre's documents, Trillium is one of Canada's largest community hospitals. Trillium created an Accessibility Advisory Committee to audit and conduct necessary changes. In 2004, Trillium conducted a site audit and contracted an architectural firm to assist with modifications. Trillium has an annual budget for upgrades and necessary renovations in order to provide barrier-free access to care. In addition to renovations and structural upgrades, Trillium has conducted disability awareness training workshops for the staff.[243]

Healthcare in Manitoba

Manitoba's Ministry of Health and Ministry of Healthy Living provide leadership in health care delivery for all Manitobans. The vision statement is "healthy Manitobans through an appropriate balance of prevention and care."[244]

The Ministry is organized into six areas: Corporate and Provincial Program Support; Primary Care & Healthy Living; Health Workforce; Regional Affairs; Administration, Finance and Accountability, and Public Health.[245] The budget for 2008-2009 was $4.371 million,[246] and as of March 31, 2009, there were 1,209,401 residents registered with the health care insurance plan.

Healthcare in Saskatchewan

The Ministry of Health, through thirteen Regional Health Authorities is responsible for the delivery of necessary health and medical services in Saskatchewan. "The Ministry strives to improve the quality and accessibility of publicly funded and publicly administered health care in Saskatchewan."[247] The Ministry is organized into 16 branches – "each working to ensure that the province's health care system operates in an effective and sustainable manner while remaining accountable to the people of Saskatchewan."[248]

The health budget for 2010-2011 is $4.202 billion and the largest portion (74%) will go toward paying health care workers. As of March 31, 2009, there were 1,836 physicians licensed to practice in the province and eligible to participate in the medical care insurance plan.

Healthcare in British Columbia

The British Columbia Ministry of Health Services has the responsibility of assuring citizens have access to timely and appropriate health services. Its vision is to establish "a health system that supports people to stay healthy, and when they are sick provides high quality publicly funded health care services that meet their needs."[249] There are six health

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[243] Trillium Health Centre. (2004). *Creating a Barrier-Free World: Annual Accessibility Plan 2004-2005*. Retrieved on March 8, 2010, from http://www.trilliumhealthcentre.org/about/AccessibilityPlan2004_05_v2.pdf
[244] Manitoba Health and Healthy Living. (2008). *Annual Report 2008-2009*. Retrieved on October 8, 2010, from, http://www.gov.mb.ca/health/ann/docs/0809.pdf
[245] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[246] Government of Manitoba. (2008). *Manitoba Budget 2008*. Retrieved on October 8, 2010, from, http://www.gov.mb.ca/finance/budget08/papers/budget.pdf
[247] Saskatchewan Ministry of Health. *Plan for 2010-2011*. Retrieved on October 8, 2010, from, http://www.finance.gov.sk.ca/PlanningAndReporting/2010-11/HealthPlan1011.pdf
[248] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[249] British Columbia Ministry of Health. (2007). *2007/08-2009/10 Service Plan*. Retrieved on October 8, 2010, from, http://www.bcbudget.gov.bc.ca/2007/sp/pdf/ministry/hlth.pdf

authorities that provide services under the guidance of the Ministry of Health Services. The health care budget for 2008-2009 was $13.59 billion.[250]

In 2008–2009, the Ministry of Health Services introduced, continued or enhanced a number of strategies across the span of health services. These include: population health promotion and health protection, disease and injury prevention, primary care, chronic disease management, Fair PharmaCare, ambulance services, community programs for mental health and addictions, hospital and surgical services, home care, assisted living, residential care, and end-of-life care.[251]

The Ministry has identified increasing demands on the health care system as the population ages. There is also a rise in the cost of treatments for chronic diseases and the need to purchase new technologies. In addition, "the Ministry is challenged in meeting this rising demand by increasing world-wide competition for health professionals and health workers, and the need to direct investments to maintain and improve the health system's physical infrastructure (buildings and equipment)."[252]

Healthcare in Yukon

The Department of Health and Social Services is responsible for the delivery of necessary health and medical services in Yukon with a budget of $257,271,000.[253] The mission is to "commit the department and its employees to quality health and social services for Yukoners."[254]

Some of the issues in health delivery are:

- "Effective linkages and coordination of existing services and service providers;
- Recruitment and retention of qualified health care professionals;
- Increasing costs related to service delivery;
- Increasing costs related to changing demographics; and
- Acquiring and maintaining new and advanced high-technology diagnostic and treatment equipment."[255]

According to Health Canada, there are fifty-eight general/family practitioners, nine specialists, and one dentist offering services to about 33,000 residents.

Healthcare in Northwest Territories

The Department of Health and Social Services, seven Heath and Social Services Authorities, and the Tlicho Community Services Agency are responsible for delivery of health services in the Territory. "The Department's mission is to promote, protect and provide for the health

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[250] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[251] *Ibid*
[252] British Columbia Ministry of Health. (2007). *2007/08-2009/10 Service Plan*. Retrieved on October 8, 2010, from, http://www.bcbudget.gov.bc.ca/2007/sp/pdf/ministry/hlth.pdf
[253] Yukon Health and Social Services. (2010). *Financial Information: 2010/2011.* Retrieved on March 24, 2011, from, http://www.finance.gov.yk.ca/pdf/budget/2011_12_fininfo_e.pdf
[254] Yukon Health and Social Services. *Web Site*. Retrieved on October 8, 2010, from, http://www.hss.gov.yk.ca/mission.php
[255] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf

and well-being of the people of the Northwest Territories."[256] The operating budget is $326 million.[257]

Healthcare in Nunavut

The Department of Health and Social Services ensures that residents receive proper services and its mission is "to promote, protect and provide for the health and well-being of Nunavut residents, in support of leading self-reliant and productive lives."[258] In 2009, the Department issued *Tamapta: Building Our Future Together 2009-2013*[259] strategic plan. The delivery of health care is based on a primary health care model. The budget for 2008-2009 was $251,388,000.[260] "Over one quarter of the Department's total operational budget is spent on costs associated with medical travel and treatment provided in out-of-territory facilities."[261]

There are 134 general/family practitioners and eighty-four specialists, and Nunavut has been trying to address the acute shortage of nurses.

The Direction of health care in Canada: Barrier-Free Health and Medical Services

The disability rate in Canada is on the rise. Presently, one in seven Canadians has a disability.[262] As the number of individuals with disabilities grows, so too does the need for barrier-free access to health and medical care and services.

In the 2006 PALS, 15.8% of participants reported that they do not have appropriate access to health care services and most of their medical and health needs go unmet. The reasons are expenses for transportation or out-of-the pocket medical expenses and a lack of availability of services in the area of residency. In addition, 21.5% reported that they were not sure how to obtain the health care services that they needed.[263]

The federal, provincial, and territorial governments support various program and projects that are set up to eliminate barriers to full inclusion for people with disabilities. Various reports have been produced by different government departments, but they rely on statistical data from surveys conducted in 2001 and 2006.[264] Today, programs are set up as a result of findings that were collected in 2006 and, therefore, do not reflect current changes in the health care systems.

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[256] Northwest Territories Health and Social Services. *Web Site*. Retrieved on October 8, 2010, from, http://www.hlthss.gov.nt.ca/english/our_system/about_us/hss_department.htm
[257] Northwest Territories Ministry of Finance. *Web Site*. Retrieved on October 8, 2010, from, http://www.fin.gov.nt.ca/address/index.htm
[258] Nunavut Health and Social Services. *Web Site*. Retrieved on October 8, 2010, from, http://www.gov.nu.ca/health/
[259] The Government of Nunavut. (2009). *Tamapta: Building Our Future Together 2009-2013*. Retrieved on October 8, 2010, from, http://www.gov.nu.ca/files/Tamapta%20Action%20Plan_ENG.pdf
[260] Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf
[261] *Ibid*
[262] *Ibid*
[263] *Ibid*
[264] Government of Canada. (2009*). 2009 Federal Disability Report*. Retrieved on September 28, 2010, from http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2008/fdr_2008.pdf

Age group	2001			2006 Comparable		
	Total Population	Population with Disabilities	Disability Rate	Total Population	Population with Disabilities	Disability Rate
Total: 0 to 14	**5 546 010**	**180 920**	**3.3%**	**5 408 580**	**200 460**	**3.7%**
0 to 4	1 641 680	26 210	1.6%	1 635 860	27 280	1.7%
5 to 14	3 904 330	154 710	4.0%	3 772 720	173 180	4.6%
Total: 15 and over	**23 445 760**	**3 420 330**	**14.6%**	**25 172 660**	**4 162 690**	**16.5%**
15 to 64	19 858 350	1 968 490	9.9%	21 175 880	2 437 610	11.5%
65 and over	3 587 410	1 451 840	40.5%	3 996 790	1 725 080	43.2%
Total: All ages	**28 991 770**	**3 601 250**	**12.4%**	**30 581 240**	**4 363 150**	**14.3%**

Figure 25: Prevalence of Disability by age group, 2001 and 2006 comparable[265] (Source: Participation and Activity Limitation Survey, 2006)

According to the 2006 PALS, transportation still remains a major barrier for people with disabilities when accessing health and medical services. According to the Government of Canada, 12.3% of the people that responded to the 2006 PALS stated that their reason for being housebound is because accessible transportation is not available. For 24.2%, the reason is because there is no assistance once they arrive at their destination.

Reason	Number	%
Total	**208 540**	—
Boarding or disembarking	65 880	31.6
Hearing announcements	17 120	8.2
Lack of appropriate transportation to and from terminal or station	28 570	13.7
Moving around terminal or station	49 350	23.7
Need an attendant to help	38 490	18.5
Ride aggravates condition	134 990	64.7
Seating on board	42 110	20.2
Seeing signs or notices	29 190	14.0
Too costly	41 020	19.7
Transporting wheelchair or other specialized aids	33 300	16.0
Unsupportive staff	33 740	16.2
Washroom facilities	39 870	80.8
Other reason	51 700	24.8

1. The chart uses 2006 data that is comparable to 2001 data.
2. Respondents could choose more than one option.
3. Not applicable to children aged 0 to 14.

Source: Participation and Activity Limitation Survey, 2006.

Figure 26: Reasons preventing long-distance travel, 2006[266] (Source: Participation and Activity Limitation Survey, 2006)

In 2007, the Canadian Transportation Agency conducted hearings regarding medical oxygen usage during transportation and found that there are many obstacles for individuals using this type of medical equipment. The Agency issued a decision, 336-AT-A-2008, which ruled that passengers should be allowed to carry their own medical oxygen and that this is according to the safety rules and regulations.

Another issue considered by the Canadian Transportation Agency was regarding allergies. The Agency is currently considering how to create barrier-free environments for people with severe allergies without limiting transportation for other individuals.

[265] *Ibid*
[266] *Ibid*

In 2003, the Canadian Transportation Agency ruled that VIA Rail had to improve physical accessibility of its cars and create barrier-free access for people with physical disabilities.[267]

Effort is needed to "inform the public about available treatments, and to motivate primary care physicians to recognize and treat" various conditions experienced by people with disabilities.[268] People with disabilities, especially individuals with mental health issues, are less inclined to seek medical assistance because of the scepticism that is demonstrated by health professionals concerning various symptoms. As David Mechanic points out "the magnitude and severity of distress and disability are the most important determinants of perceiving a need for care."[269] Mechanic also states the following:

> "the processes that define how persons with symptoms identify need and decide to seek care are common to most types of illness. However, the values measured on predictors such as perceived stigma, insurance coverage, expectations of treatment benefits, and the like may vary a great deal from one illness to another."[270]

The term *reasonable access* from the Canada Health Act has not been defined. The questions are who decides what services are *medically necessary,*[271]and how will individuals be able to receive the necessary care in appropriate timeframe.

There is a great need to close the gaps in the current health systems between the need for medical services and the actual care that is being delivered to people with disabilities. "Behavioural research makes clear that knowledge by itself is not a sufficient inducement to bring people into needed care."[272] How to allocate resources has become a great challenge for policymakers. The demand for services and care is constantly increasing.[273] Morris recommends that if we want to eliminate barriers to health care then "a mobilization of professional-expert opinion" is necessary, but he admits that the likelihood of that happening is very slim.[274] Without all parties that are involved in the health care service delivery coming together solutions will always remain inequitable.

According to Casebeer and Reay, "when family physicians actively participate in reform, effective changes happen" and this is what is necessary in Alberta and in Canada.[275] The primary health care service delivery is in need of change because many individuals do not receive the much needed medical treatment and prevention they require. Studies have shown that today "family physicians are playing critical roles in developing innovative solutions to long-standing problems" by creating environments where "joint leadership" is encouraged and developed.

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[267] *Ibid*
[268] Mechanic, D. (2002). *Removing Barriers to Care among Persons with Psychiatric Symptoms*. Retrieved on September 28, 2010, from http://content.healthaffairs.org/cgi/reprint/21/3/137
[269] *Ibid*
[270] *Ibid*
[271] Health Canada. (2001). *Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada*. Retrieved on September 28, 2010, from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-certain-equit-acces/2001-certain-equit-acces-eng.pdf
[272] *Ibid*
[273] Morris, R. (1965). *Next Steps in Removing Barriers to Health Care*. Retrieved on September 28, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1750845/pdf/bullnyacadmed00285-0086.pdf
[274] *Ibid*
[275] Casebeer, A. and Reay, T. (2004). Reinventing Primary Health Care: Physicians Have a Pivotal Part to Play. *Canadian Family Physician VOL 50: OCTOBER*. Retrieved on September 28, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2214508/pdf/15526866.pdf

Family physicians are establishing new settings by "working together with other health care providers" and encouraging collaborative and innovative ways of delivering care. In addition, physicians in Alberta are "partnering with social service and education and community representatives" and creating a wider pool of resources. Each of these innovations and changes are intended to provide "continued provision of high-quality primary care" and understand the needs of patients.[276] Only with continued changes and collaboration will the barriers that exist in the system be eliminated. We need to continue to educate ourselves. As Gregor Wolbring writes, "solutions follow perceptions and perceptions are changed by solutions."[277]

In 2001, the US Institute of Medicine stated that improving access to health care will be possible only if polices are based on the following practicalities: "safe, effective, patient-centered, timely, efficient, and equitable."[278] In a report produced by the Canadian Health Services Research Foundation, primary health care has to be based on principles such as "effectiveness, productivity, accessibility, continuity, quality, and responsiveness."[279]

Research has shown that when citizens have quality access to primary health care, then health and well-being is higher and incidences of developing chronic diseases are lower. Glazier points out,

> "despite this high level of innovation in every province and territory, there is no coordinated national plan for evaluation. Innovations often attract those most able to learn about them and experience their benefits and there are concerns that the needs of disadvantaged and vulnerable populations are not being specifically addressed in most primary care reform efforts. Nationally coordinated strategies are needed to ensure that primary care reform is appropriately evaluated and that mid-course corrections can be made to ensure effectiveness and equity."[280]

Any changes within the current health care service delivery have to be supported by strong political leadership and the desire to undertake major system overhaul. In addition, these changes have to incorporate societal demands for types of care – what people need cannot be ignored. "Societal attitudes can help overcome governmental barriers."[281] Any health reforms must be applicable to all levels and types of service providers if the desire is for measured outcomes to be positive and significant.

No changes will be effective if the patient is not consulted. "In today's information-rich society, where patients are apt to see themselves as health care *consumers* with options and rights, some jurisdictions are setting down those rights in formal bills of rights or

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[276] *Ibid*

[277] Wolbring, Gregor. (2005). *The Triangle of Enhancement Medicine, Disabled People, and the Concept of Health: a New Challenge for HTA, Health Research, and Health Policy*. Retrieved on September 28, 2010, from http://www.ihe.ca/documents/HTA-FR23.pdf

[278] Iezzoni, L. (2003). Targeting Health Care Improvement for People with Disabilities. *International Journal for Quality in Health Care 2003: Volume 15, Number 4, pp. 279-281*. Retrieved on September 28, 2010, from http://intqhc.oxfordjournals.org/content/15/4/279.full.pdf+html

[279] Canadian Health Services Research Foundation. (2003). Choices *for Change: The Path for Reconstructing Primary Health Care Services in Canada*. Retrieved on September 28, 2010, from http://www.chsrf.ca/final_research/commissioned_research/policy_synthesis/pdf/choices_for_change_e.pdf

[280] Glazier, Richard. (2007). Balancing Equity Issues in Health Systems: Perspectives of Primary Health Care. *Healthcare Papers, 8(Sp) 2007: 35-45*. Retrieved on September 28, 2010, from http://www.longwoods.com/content/19218

[281] Institute for Clinical Evaluative Sciences. (2009). *What Does it Take to Make a Healthy Province? A Benchmark Study of Jurisdictions in Canada and Around the World with the Highest Levels of Health and the Best Health Behaviours: ICES Investigative Report.* Retrieved on September 28, 2010, from http://www.ices.on.ca/file/Healthy%20province%20November%20release.pdf

charters."[282] Alberta is developing a Health Charter. The United Kingdom and New Zealand have developed and implemented a code of rights for health care consumers.[283]

Many critics have argued that rights and obligations do not create seamless systems of care delivery but increase the financial investments need to support health care systems.[284] Consumer involvement in decision making is vital for the future of health care in Canada.[285] "Citizens wish not only to preserve and protect the best of the Medicare system built over recent decades but also to update it and to make it sustainable for the future."[286]

According to a report released in 2008, the Government of Canada acknowledged the following:

> "creating accessible communities and providing disability supports is integral to achieving the full participation of people with disabilities in Canadian society. This approach requires action on two levels: at the societal level, the reduction or elimination of the environmental barriers that affect the lives of people with disabilities and prevent their full inclusion in society; and, on a personal level, the availability of disability supports that address individual needs, further participation and maximize independence."[287]

Recognizing a need for communities that are accessible and inclusive is an important step towards eliminating the disparity between those with disabilities and those without disabilities.

Community Engagement

According to Mitton et all, "there seems to be no clear consensus in the literature on when public engagement should be sought, how it should be obtained, or how it might be incorporated by decision-makers into priority setting and resource allocation processes."[288]

Public engagement is defined as "processes [that] are characterized by bilateral and deliberative dialogue, mutual respect, power sharing, and in some instances, long-term partnership between citizens and government."[289] The term "engagement" has been distinguished from the term "consultations." The first relates to obligation and the second to opinion.

The reason for public engagement is that people are generally interested in health care. They tend to be vocal about decisions that undermine personal interests. Decision-makers have been reluctant to seek public engagement, because, as Steven Lewis points out, "in the face of such complex issues, there is a public that has a relatively stable and even apprehendable

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[282] Commission on the Future of Health Care in Canada. (2002). *Access to health care in Canada*. Retrieved on March 8, 2010, from http://www.chsrf.ca/other_documents/romanow/pdf/accesstocare_e.pdf
[283] *Ibid*
[284] *Ibid*
[285] MacKinnon, M., Maxwell, J., Rosell, S. and Saxena, N. (2003). *Citizens' Dialogue on Canada's Future: A 21st Century Social Contract.* Retrieved on March 8, 2010, from http://www.owr.ca/19110_en.pdf
[286] Commission on the Future of Health Care in Canada. (2002). *Report on Citizens' Dialogue on the Future of Health Care in Canada*. Retrieved on March 8, 2010, from http://www.cprn.org/documents/12704_en.PDF
[287] Government of Canada. (2008). *2008 Federal Disability Report*. Retrieved on September 28, 2010, from http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2008/fdr_2008.pdf
[288] Mitton, C., Smith, N., Peacock, S., Evoy, B. and Abelson, J. (2009). Public Participation in Health Care Priority Setting: A Scoping Review. *Health Policy 91 (2009) 219–228.* Retrieved on March 8, 2010, from http://www.canprep.ca/library/Public_Participation_in_Priority_Setting.pdf
[289] UBC Centre for Health Services and Policy Research. (2007). *Voices and Choices: Public Engagement in Health Care Policy*. Retrieved on March 8, 2010, from http://www.chspr.ubc.ca/files/publications/2007/chspr07-11.pdf

point of view. And this leads to the question: Is health care policy an appropriate field in which to be investing in public engagement?"[290]

There have been many instances where public engagement has been integrated in the health care decision-making process. "Effective community engagement brings people to the table – both community members and professionals – and nurtures their active participation in all aspects of decision-making processes."[291]

Alberta recently completed a consultation process that asked "Albertans to share their views on four areas: Principles, Patient Charter, New Legislation and Consulting Albertans."[292]

In Ontario, "Local Health Integration Networks were created in 2006 with an explicit mandate to engage stakeholders and their communities. More than this, the idea of engagement was central to their rationale. Proponents of the LHIN system argued that regional planning authorities would be better positioned than ministry officials to assess and interpret local needs. LHINs could do this because they would be in closer contact with the communities they served and because of the strength and number of local relationships they could forge and sustain."[293] Ontario's LHIN's used the following formula as a guide for public engagement:

Purpose + Context + People + Process = Outcome[294]

In British Columbia, public engagement[295] was sought by the Vancouver Coast Health Regional Authority and this "is the only health authority in Canada with a dedicated community engagement team."[296] This team is focused on engaging the public and seeking input on how to improve services and maintain healthy communities. Additionally, in 2006 the BC provincial government launched a campaign of public engagement and asked for input on health priorities and for ideas of how to create a sustainable system.

Many countries like Australia and New Zealand, have sought public engagement in the development of rural health policies.[297] The Northern Ontario School of Medicine has also incorporated public engagement with the intent to minimize the challenges felt by residents living in rural and remote areas in Ontario:

> "Through community engagement, community members are actively involved in hosting students and contributing to their educative experience. Community engagement for NOSM is consistent with its social accountability mandate and has a particular focus on collaborative relationships with Aboriginal communities and organizations, Francophone communities and organizations, and rural and remote communities, as well as the larger urban centres of Northern Ontario. For NOSM, community

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[290] *Ibid*
[291] Minnesota Department of Health. (2002). *Strategies for Public Health: A Compendium of Ideas, Experience, and Research From Minnesota's Public Health Professionals*. Retrieved on March 8, 2010, from http://www.health.state.mn.us/strategies/engagement.pdf
[292] Alberta Health and Wellness. (2010). *Putting People First: A Summary of Albertans' Views*. Retrieved on November 8, 2010, from http://www.health.alberta.ca/documents/Alberta-Health-Act-Summary-2010.pdf
[293] MASS LBP. (2009). *Engaging with Impact: Targets and Indicators for Successful Community Engagement by Ontario's Local Health Integration Networks: A Citizens' Report from Kingston, Richmond Hill and Thunder Bay*. Retrieved on March 8, 2010, from http://www.masslbp.com/media/engagingreport.pdf
[294] *Ibid*
[295] Vancouver Costal Health. (2009). *Community Engagement Framework*. Retrieved on March 8, 2010, from http://www.vch.ca/get_involved/community_engagement/
[296] UBC Centre for Health Services and Policy Research. (2007). *Voices and Choices: Public Engagement in Health Care Policy*. Retrieved on March 8, 2010, from
[297] Strasser, Roger. (2010). Community Engagement: A Key to Successful Rural Clinical Education. *Rural and Remote Health* 10: 1543. (Online), 2010. Retrieved on November 10, 2010, from http://www.rrh.org.au/publishedarticles/article_print_1543.pdf

> engagement occurs through interdependent partnerships between the School and the communities whereby the communities, through local NOSM groups, are as much a part of NOSM as the main campuses in Thunder Bay and Sudbury. These relationships are fostered through the Aboriginal Reference Group, the Francophone Reference Group, local NOSM groups, and a vast network of formal affiliation agreements and memoranda of understanding."[298]

The report states that implementing public engagement by the Northern Ontario School of Medicine was not an easy task. The challenge was how to eliminate the assumptions by the "conventional wisdom that the University is an ivory tower separated from the 'real world' community."[299]

According to Bruni et all, public engagement in health care is vital because: "(1) the public is the most important stakeholder in the health care system; (2) engaging the public is in keeping with the principles of a democracy; (3) members of the public can provide insights on the values and priorities of their communities; and (4) engaging the public can lead to improved public trust and confidence in the health care system."[300]

As Bryan Burns states, public engagement has evolved over time and today engagement is characterized by the following steps:

- Inform (step 1)
- Consult (step 2)
- Involve (step 3)
- Collaborate (step 4)
- Partner (step 5)
- Delegate Authority (step 6)
- Establish Autonomy (step 7)
- Advise (step 8)
- Enable (step 9)[301]

However, public engagement has its limitations such as time, resources and expertise in conducting these kinds of activities.[302] As Abelson and Gauvin point out, there tends to be "lack of commitment to evaluation from senior management". [303] The challenge is how to evaluate public engagement because of the "the complexity and value-laden nature of public participation as a concept; the absence of widely held criteria for judging its success and failure; the lack of agreed-upon evaluation methods; and the paucity of reliable measurement tools."[304]

Citizens participate in public engagement because they "need to have a voice in defining accountability, the roles, responsibilities and relationships among all parties involved and in

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[298] *Ibid*
[299] *Ibid*
[300] Bruni, R., Laupacis, A. and Martin, D. Public Engagement in Setting priorities in Health Care. *Canadian Medical Association Journal*. July 1, 2008: 179(1). Retrieved on November 10, 2010 from http://www.cmaj.ca/cgi/reprint/179/1/15
[301] Bruns, Bryan. (2003). *Water Tenure Reform: Developing an Extended Ladder of Participation*. Retrieved on November 10, 2010 from http://www.bryanbruns.com/bruns-ladder.pdf
[302] Abelson, J. and Gauvin, F. (2006). *Assessing the Impacts of Public Participation: Concepts, Evidence and Policy Implications*. Retrieved on November 10, 2010 from http://www.cprn.org/documents/42669_fr.pdf
[303] *Ibid*
[304] *Ibid*

determining what mechanisms are needed and acceptable to uphold that trust."[305] If the message provided by the government is not clear then the public does not see how it can provide constructive opinions. Regardless of realization public engagement in health care decision-making, citizens will continue to hold the government accountable for their actions and service delivery.

[305] Abelson, J. and Gauvin, F. (2004*). Transparency, Trust and Citizen Engagement: What Canadians are Saying about Accountability*. Retrieved on November 10, 2010 from http://cprn.org/documents/33621_en.pdf

Needs Assessment: Assessing the Needs of Albertans with Disabilities

From April to July 2010, ACCD conducted a multi-part needs assessment process to determine barriers that people with disabilities experience in Alberta. Given that the review of literature indicated the importance of creating health care that is responsive to the needs of all citizens; it was essential to solicit input from people with disabilities, not-for-profit organizations, and health care professionals. A balance of urban and rural consultation was sought in each phase. Despite this diversity, each phase reported similar themes.

As part of the needs assessment, ACCD hosted six community consultations across the province. The goals of the community consultations were to inform, consult and involve the public in the development of recommendations for barrier-free health and medical services in Alberta for the benefit of all citizens.

The needs assessment process included distribution of questionnaires to people with disabilities and health care professionals. These questionnaires gathered the perceived barriers of individuals who are accessing the system and individuals who are in the system providing services.

Each phase of the needs assessment reported common themes. Most notably, all phases reported that there are barriers in the health care system – barriers that are being created in response to current policymaking without seeking input from patients and health care professionals. Participants overwhelmingly presented the need for a diverse range of services and for the government to assist health care professionals in providing appropriate and timely services. Every consulted location has been significantly affected by current government restructuring of services and lack of funding for health care professionals to provide timely and appropriate health care services.

This section provides a thorough description of the format, data collection methods, and results of each phase of the needs assessment, including thematic highlights. The section concludes with a summary of key messages from all needs assessment phases.

Community Consultations: A Summary Report on the Findings

Introduction

Between May 30 and June 11, 2010, ACCD hosted six community consultations attended by people with disabilities, not-for-profit organizations, government representatives of various funding programs, and family members. The community consultations were about sharing information and exploring the unique barriers that are being faced by Albertans with disabilities when accessing health and medical services. The goals of the consultations were to inform, consult, and involve the public in the development of recommendations for barrier-free health and medical services in Alberta. The consultation process made it possible for ACCD to collect information directly from citizens with disabilities, their families, community agencies, and health care professionals in Alberta.

Community consultations were held at the following locations: Edmonton (May 20, 2010), Calgary (May 31, 2010), Vegreville (June 3, 2010), Rocky Mountain House (June 4, 2010), Lethbridge (June 7, 2010) and Grande Prairie (June 11, 2010).[306] A press release was conducted on April 26, 2010 to inform the media about the project and the community consultations. Information about the consultations was distributed through promotional e-mails, and individuals were asked to register. 114 Albertans attended the community consultations and 109 requested follow-up contact concerning the project.

Consultation Format

The same agenda and processes were used in all sessions. Representatives of ACCD opened the sessions by welcoming participants and presenting an overview of the organization, the purpose of the session, and how the information will be used.

Participants were asked to introduce themselves and respond to the following question:

> '*The reason I attended this community consultation is...*'

Some of the answers were:

- Lack of initiatives by Alberta Health and Wellness to assist people with disabilities in the system.
- I am not able to receive proper x-ray exams.
- People travel to other provinces and countries in order to access appropriate rehabilitation services. We need good services in Alberta.
- I have an interest in eliminating barriers to health and emergency room services.
- To bring issues forward experienced by people with brain injury.
- I am here to bring in the parent perspective and the struggles in navigating the system.
- I am here to share my experiences about the challenges of blind Albertans.
- I am here to present my struggles and to see how I can get some help.
- To speak about the issues that people in rural Alberta face every day.

[306] The summaries from each community consultation can be viewed in Appendix I.

- My challenges with inaccessible exam rooms and medical laboratories.
- How to access mental health supports and services?
- There are too many issues for people with spinal cord injury when comes to health care services.
- To learn how the rest of the community is coping.
- To raise awareness about the DeafBlind community and the barriers faced.
- To present issues about the struggle that people with autism have from childhood to adulthood.
- I would like to know how to navigate the system and find services.
- What can be done about the deterioration of the system?
- Without barrier-free health services, people with disabilities cannot keep jobs.
- Healthcare access is limited when you have a chemical sensitivity.
- There is no recognition for invisible disabilities.
- I need to receive better education and awareness about various services. It seems that I am slipping through the cracks of the system.
- I am frustrated with the lack of transition services for children who turn 18.
- To bring forward the concerns of the hard of hearing community.
- I am facing many barriers at doctor's offices and universal design implementation is my goal.
- We have to travel in order to access service.
- To bring some of the FASD concerns.
- To see how I can help my son in his struggles.
- To see what others are saying and how I can contribute.
- I am here on behalf of brain injury clients and to present some of the communication barriers.
- So far I have found doctors very supportive and accessibility is very good.
- I have experienced barriers with the home care system.
- To share some of the many attitudinal barriers that I have experienced.[307]

Following this warm-up exercise, participants worked in small groups to identify the challenges and potential solutions, all of which were recorded on sheets of paper posted on the walls. Each workshop was approximately three hours long.

Data Collection

At the conclusion of each consultation session, the facilitator gathered the charts containing participants' identified challenges and solutions. The common themes identified in each session have been included in the summary below. Closely related themes with significant overlap, however, have been combined for the sake of clarity.

Overview of the Findings

Generally, participants identified the same key challenges and solutions regardless of location. The most reoccurring challenges were concerns about the health care system and medical professionals, lack of access to health and medical services, and inaccessibility of

[307] These statements were recorded on a flip chart and are verbatim.

medical clinics and medical equipment. In addition, issues concerning transportation, information and referral, advocacy, lack of government accountability, and caregiver challenges were discussed.

The following challenges were common to most settings.

Concerns with the health system and medical professionals

- The waiting lists for seeing specialists are very long and this problem is worse in rural areas where people have to travel to other locations in order to access specialists.
- Many communities are experiencing high turnover of health and medical staff, and patients need to start over with every new staff that comes to their location.
- Smaller communities expressed the concern that health and medical staff do not stay very long.
- There are six doctors in a community that needs at least twelve.
- Many general practitioners and specialists refuse to fill out forms because they do not know the patient. As a result, the patient is not able to access funding services like AISH or CPP.
- Because of the low number of general practitioners in many locations, acceptance of new patients is virtually nonexistent.
- Health and medical staff are fearful to assist individuals to get on the examining table.
- There is a lack of appropriate patient history knowledge transfer when medical professionals leave a community.
- Medical professionals do not have time allocated to fill out forms, talk to the patients and provide appropriate directions because of the number of patients they have to see every day.
- Short allocations for appointment times.
- Lack of treatment consistencies between doctors educated in Canada and doctors educated in other countries.
- People with disabilities are last to receive care in the emergency room.
- Prejudice within the medical system towards people with disabilities. They are perceived as a burden to the health system.
- Staff does not have appropriate knowledge about various disabilities, how to communicate and identify needs, and to understand behaviours and reactions to situations.
- Walk-in-clinics should not be a source for primary patient care.
- There is a lack of choice for specialists. One specialist serving a large area and no options to choose someone else.
- Medical professionals do not utilize community advocates to assist people with disabilities with their health and medical needs.
- There is a shortage of health care professionals who are willing to work and assist individuals with disabilities.
- There are many attitudinal barriers for people with disabilities and their families when accessing health and medical services.
- People with multiple disabilities tend to receive services for one disability and be denied other necessary services.

- Healthcare professionals do not understand the system well enough to assist people in accessing necessary services.
- Lack of specialized disability clinics.
- Non-inclusion of the patient as part of the team.
- Medical professionals are strapped for time and training.
- People are being sent home without explaining how to use equipment.
- Doctors are affected by cutbacks and patients are experiencing the consequences.
- Lack of appropriate funding necessary for health professionals to train and improve their knowledge.
- Attitudes toward individuals with mental health that "we do not deal with people like that."
- Negative attitudes at medical clinics – "what is wrong with him?"

Lack of access to health and medical services

- Individuals have to wait extensively to access medical tests and exams.
- There is a lack of transition of services from children to adult services.
- Individuals are not able to obtain diagnosis in a timely manner, leading to barriers in accessing necessary health and medical services.
- Individuals that are not able to access proper mental health services tend to end up in jail, the street or the hospital. Individuals have to go from department to department to locate someone who will assist them.
- Many financial barriers are in place now that prevent people from accessing services.
- There is one x-ray room in many rural hospitals; consequently wait times for access for this service is very long.
- Travelling specialized services come once a year in many rural locations.
- Because of inappropriate long term care and supportive living accommodations, people are transferred away from their communities.
- People with disabilities have difficulties in accessing and searching for available services.
- Single-service providers for community services has proven to be an ineffective model because of long waiting lists, exclusionary criteria, must-fit-in certain criteria, and not consumer-directed.
- Lack of follow up services after hospitalization.
- Lack of collaboration between PDD and Alberta Health Services.
- Lack of funding to conduct appropriate assessments.
- Access to services has been compromised because of cuts to funding.
- Need better integration of service providers and easier transfer of medical information.

Inaccessibility of medical clinics and equipment

- There is a lack of standards for clinics and offices concerning accessible parking, waiting room, and patient rooms.
- Exam rooms are very small to accommodate individuals that use wheelchairs/scooters.
- Merely few clinics have weight scales for individuals that use wheelchairs/scooters.

- Lack of height-adjustable examination tables and equipment for various tests.
- Reception desks are not appropriately designed for wheelchair/scooter users.
- Specialized equipment not readily available, even in medical facilities.
- The travelling specialist clinic transportation is not accessible for people with disabilities.
- Lack of funding for new communication devices, alternative communication materials, and interpreters.

Transportation

- People use the ambulance frequently because of the lack of appropriate transportation systems.
- There is a lack of appropriate transportation system to access health and medical services. People have to rely on their families, friends, and neighbours if they are to get to any kind of services.
- People incur very high transportation expenses when accessing services outside of their communities.
- Lack of accessible taxis. Very few to serve many.
- Lack of organizations that can assist people with disabilities to and from medical appointments.
- Lack of late night transportation to emergency services.

Advocacy and navigation of the system

- Advocates have to act as detectives in order to assist their clients in accessing health and medical services.
- There is lack of a standard processes when assisting people with disabilities.
- Lack of information and referral services.
- People tend to be viewed as a nuisance when trying to ask for information and referral services.
- Disconnect between service provider agencies and the government departments that fund the services.
- How to navigate a system that is not understood even by the individuals who work in it?
- Organizations play a guessing game with reference to what can be funded and what cannot.
- Referrals have a tendency to cost money to families that are navigating the system.

Lack of government responsibilities

- The Alberta Building Code is not properly enforced.
- Failure to promote barrier-free and universal design.
- What is the exact number of people with disabilities in Alberta? Is the government collecting any information in order to allocate appropriate services?
- Lack of ombudsman for people with disabilities that can lead to policy changes.
- Many ambiguities in jurisdiction processes for various programs.
- Service providers need to be consumer driven and held accountable.
- Lack of media coverage on issues that people with disabilities experience.

- The health care Act needs changes to reflect more of society's current needs.
- Minimum requirements for accessibility need to be raised in order to reflect the needs of the population.
- Provincial disparity between cities and rural programs.
- Lack of appropriate knowledge of various funding programs.
- Non-existent transition processes from children services to adult services.

Home care, caregiver and respite care supports

- There is a shortage of qualified caregivers, so families have difficulty finding paid staff to help and relieve them.
- Respite is designed for the schedule of others, not the caregiver. There is no weekend in-home respite because of staff shortages.
- Funding for caregiving involves so many complications – paperwork, HR issues, changes in staff, freedom of information regulations.
- Regional and provincial coordination of respite programs and resources is missing.

From Challenges to Solutions

The following actions and solutions were proposed by participants in response to the above challenges.

Concerns with the health system and medical professionals

- Eliminate the pay scale difference between urban and rural doctors.
- Enhance the rural Alberta recruiting program for health care professionals. Create a strategic plan of how to get more health professionals to move to rural areas and remain long term.
- Allow disability experts, advocates, guardians, support staff, and caregivers to be part of the decision-making team.
- Create a program that will recognize health care professionals that go above and beyond their duties to assist patients.
- People with disabilities should be an integral part of the decision-making medical team.
- Allowing health care professionals the time and resources to develop written reports for patients that have cognitive impairments.
- Ease the transition from child health services to adult health services.
- Assist in the removal of attitudinal barriers by health care professionals to be more patient-centred rather then seeing patients as burden.
- Reimbursement system that will allow health professionals to assist people with disabilities in an appropriate and timely manner.
- Innovative reimbursement system to allow patients with disabilities the appointment time that they need when accessing health and medical services.
- Augment the work between health professionals, Alberta Health Services, and Alberta Health and Wellness.
- Incentives for students to go into the medical profession.
- Appointments should be according to time needs (shorter for prescription renewal and longer for more complex needs).

- Pharmacist should play a bigger role in the education of patients about proper medication usage.
- There should be a medical team with various specialists set up in every community so people do not have to travel in order to access services.

Lack of access to health and medical services

- Create incentives to recruit more specialists in adult services.
- The transition of services between age 16 to 65 to 65 and over should be connected and seamless for the individual in the system.
- The ability to set up services in rural areas that will perform day surgeries which will reduce waiting times and people will be able to receive timely and appropriate services in their own communities.
- Set up of more frequent specialized traveling clinics for mammograms, bone density, foot, hearing aid etc. They work very well and people appreciate the access.
- Infrastructure for health services to be set up so people can access services in their communities.
- Remove Alberta Health Services hiring freeze in order to increase the number of health professionals assisting patients.
- More support services for individuals that are going through the rehabilitation process and living a life with a disability.
- Allow, in extreme cases, home visitations by health care professionals.
- Enhance home care services.
- Enhance community-based medical services.
- Prevent movement of services from smaller communities to larger cities.

Inaccessibility of medical clinics and equipment

- Develop standards that will guide health and medical professionals to establish accessible offices.
- New buildings should comply with the Alberta Building Code.
- A concern's line where people can call and express barrier issues, so there is a continuous record of issues.
- Mandate a minimum number of accessible exam rooms per number of patients or health care professionals.
- Provide incentives for health care professionals to establish practices in accessible offices.
- Allow grants and funding opportunities for health care professionals to make their offices accessible.
- There should be at least one place that is fully accessible where people with disabilities will be able to receive appropriate and adequate medical care.
- Medical equipment should be updated and reflect the needs of the population.

Transportation

- Money to initiate a program that will provide appropriate and necessary transportation services.
- Transportation connection between smaller communities.

- Incentives for the local taxi services to have accessible transportation.

Advocacy and navigation of the system

- Alberta Health Services needs a listing of information on social media outlets in order to inform individuals about accessible clinics and available services in their area.
- Medical receptionists should have proper training in information and referral.
- Incentives to allow health professionals to develop care manuals.
- Training for professionals to provide appropriate referrals to available mental health services, addiction, and sexual abuse programs.
- Information and referral for peer support groups.
- Provide information in plain language and alternative forms.
- Establish a coordinated information system.
- Enhance the volunteer service sector.
- Create a cross-disability information and referral navigator in each community.
- Establish uniform advocacy processes for community organizations.

Lack of government responsibilities

- Develop strategies to raise awareness about people with disabilities.
- Create a tool that will allow disability knowledge sharing among health professionals.
- Community organizations to act as information resources.
- Enhance media coverage on universal design.
- The UN Convention on the Right of Persons with Disabilities requires that the government ensure that all services that are provided for able-bodied individuals be provided to people with disabilities.
- Appropriate provision of services for people with disabilities will assure that there is no exploitation of services and inappropriate allocations.
- Financial support for networking groups.
- Establish an electronic knowledge database.
- Establish education and awareness training funding.
- Create a solid system navigation process.
- Changes to the health care rules and regulations to reflect the needs of the patient.
- Decision-makers to grasp the diversity of each community in Alberta. Many locations like Lethbridge and Grande Prairie are still considered as rural when services are allocated.

Home care, caregiver, and respite care supports

- Set up services such as a 24/7 help line with information on where respite is available, an online peer support group, and a Provincial Caregivers Network.
- Create a registry of care providers; set up cooperative and peer respite options.
- Allow living allowance for family caregivers unable to access employment.
- Create funding methods for family caregivers to access respite care services.
- Create opportunities for caregivers to be paid for the services they provide.
- Programs that will help caregivers to understand the needs of the individuals and how to cope and manage with the caregiving demands.
- Create programs that will assist caregivers in navigating the system.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. Participants at some of the community consultations provided names of physicians, specialists, dentists, and social workers.

Conclusion

The issues raised by nearly all participants were similar despite differences in location. Notwithstanding these differences, these consultations displayed strong province wide support for addressing barriers to health and medical services for people with disabilities.

Survey Results for health care Professionals: Summary of the Findings

Introduction

A survey was developed to assess the knowledge and the needs of physicians in Alberta in their provision of services to people with disabilities. It was mailed to physicians on the list from the College of Physicians and Surgeons website under the heading *Accepting New Patients*. The total number of surveys mailed on April 23, 2010 was 1020. The total number of Surveys received back by the June 30, 2010 deadline was 44, a 4.31 percentage return rate.

> *First task is to de-stigmatise disability, talk about it, and accept it.*
>
> - Comment from a Survey participant

The Survey was comprised of questions about types of practices, patients with disabilities, physical accessibility, availability of disability-related policies and procedures, and opinions regarding the current state of the health care system in Alberta.

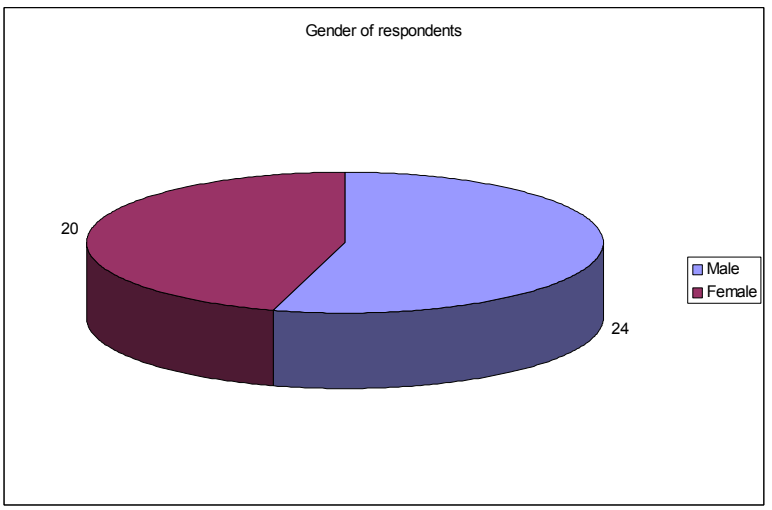
The following sections demonstrate the results from the Survey.

Survey Participant Geographical Location

The survey was mailed to 87 different locations across the province; however, we received surveys back from the following 24 locations, as shown on the map below:

Figure 27: Health professional's survey: participant locations

Gender of Participants



From our sample, 54.55% were male and 45.45% were female health practitioners.

Figure 28: Gender of respondents

Type of Practice

From the 44 participants in the survey, 29 stated that they are in a full-time medical practice, and 14 stated that they are in a part-time medical practice (one participants did not respond to this question).

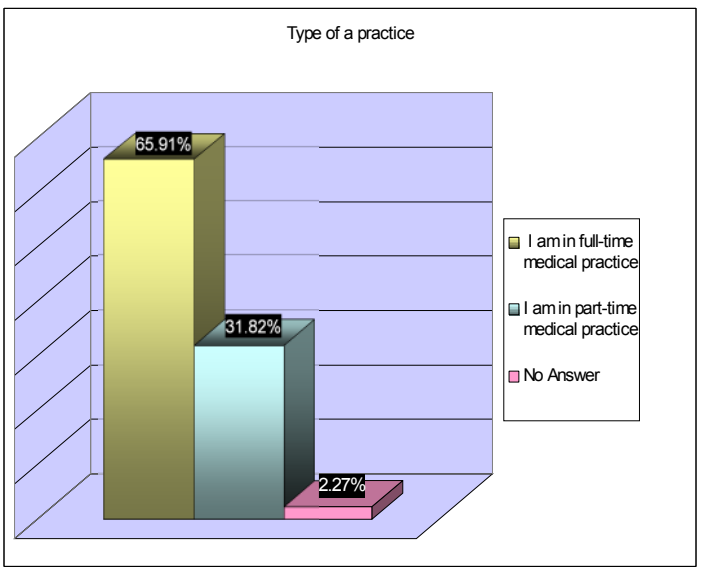


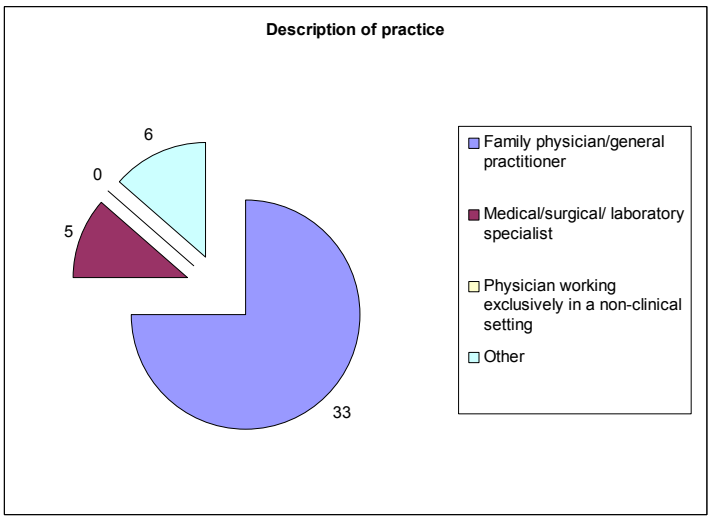
Figure 29: Type of practice

"Which of these best describes you?" and "How long has your office/clinic been open?"

From the 44 participants, 75% stated that they are best described by the statement family physician/general practitioner, 11.36% as medical/surgery/laboratory specialist, and 13.64% as one of the following:

- Palliative care/geriatrics/Pain Control Clinic
- Generalist in mental health working with developmentally disabled/delayed adults
- Mental health generalist
- Chronic pain specialist
- Emergency physician

- Phlebology and complementary medicine

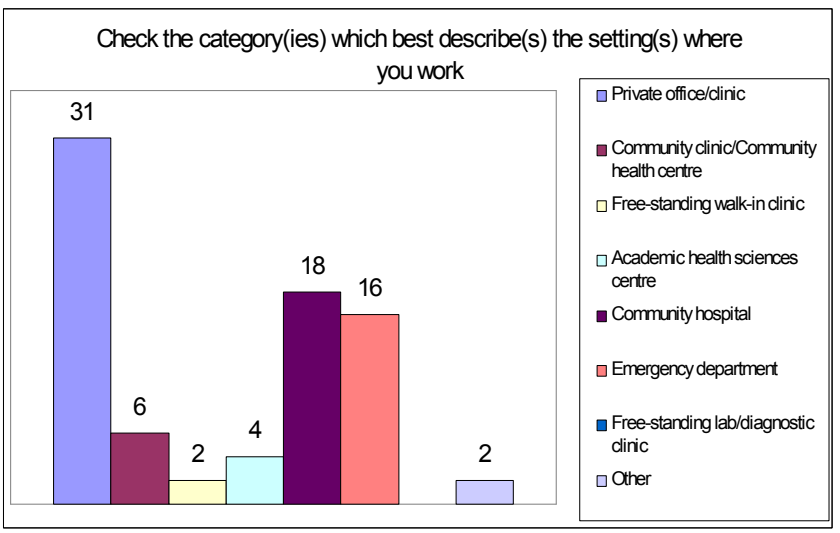


From 44 participants, 37 answered the question about the length of their practice. The average length of clinical practice is 18.18 years. The longest practice was identified as 50 years, and the shortest one year.

Figure 30: Description of practice

"The setting(s) where you work"

Twenty-two respondents reported two or more settings (multiple answers by participants). There were no survey participants that identified with Free-Standing Lab/Diagnostic Clinic settings.



Two participants identified under *other* as working in nursing homes and palliative and long term care facilities.

Figure 31: Setting(s) of work

"With respect to your MAIN patient care setting specified, describe the population PRIMARILY served by you in your practice" (multiple answers)

From the survey participants 18 serve populations primarily in urban/suburban locations. One participant serves geographically isolated locations. Out of the 44 participants, 9 respondents chose two or more settings to describe their practices.

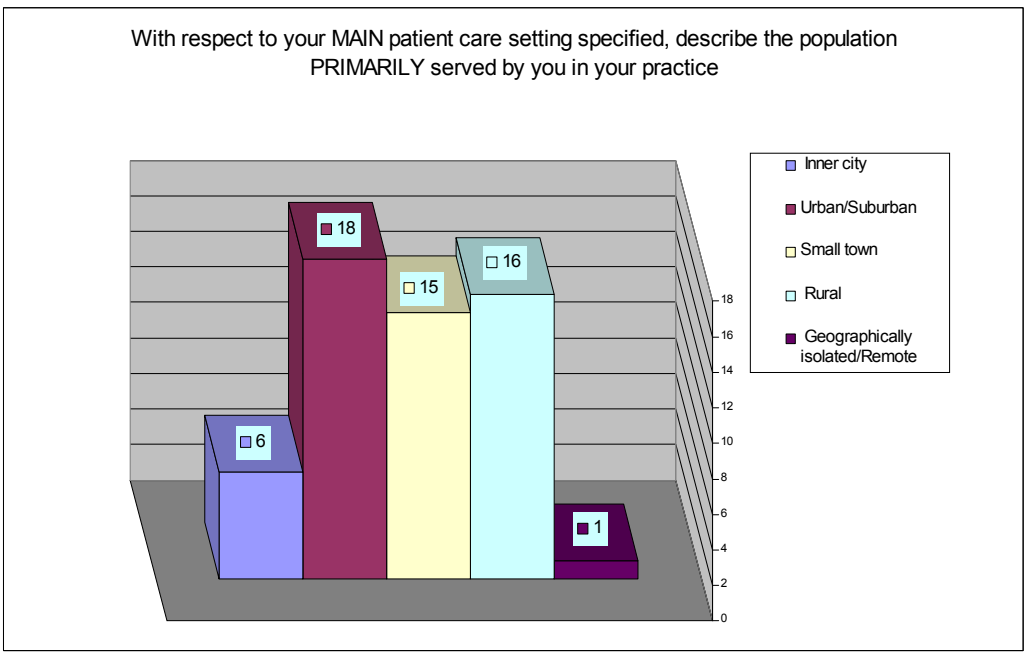


Figure 32: Main patient care setting

One respondent chose all settings as the physician receives secondary/tertiary referrals from patients from all settings.

"Why did you consider establishing your practice at your current location?"

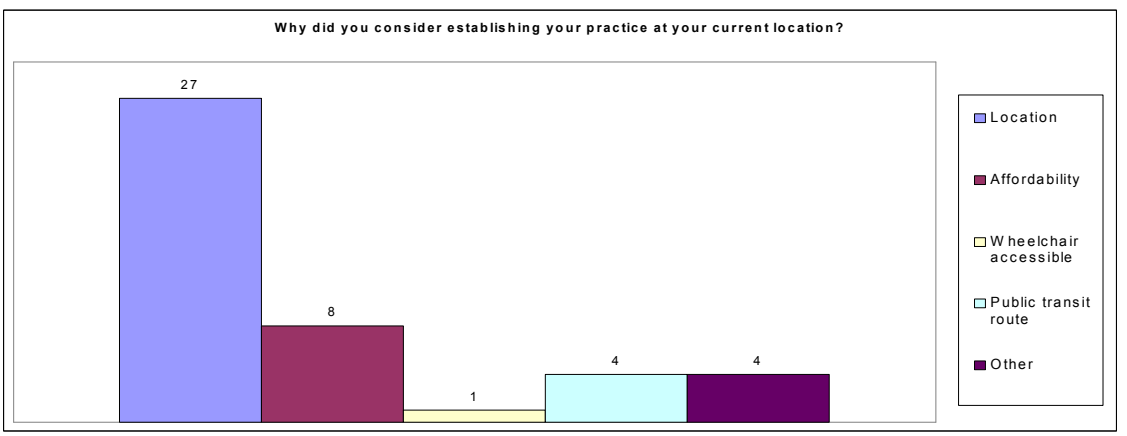


Figure 33: Reasons for practice establishment at the current location

From the total number of returned surveys, 61.35% participants chose location as a consideration for establishing their practices. For 18.18% participants, affordability was the choosing factor. Only one (2.27%) participant stated that having wheelchair access was a determining factor. For four participants (9.10%), public transit route was the determining factor and for four (9.10%) physicians, *Other* factors contributed to the decision-making.

"Please indicate with whom you regularly collaborate in providing patient care" (multiple answers)

Participants were asked to illustrate their medical collaborations. Each participant was asked to mark all collaborations that apply to his or her practice. The largest collaboration (90.69%) is conducted with other family physicians in the care of patients. The second largest collaboration (74.41%) is with mental health counsellors. 72.09% of the participants collaborate with physiotherapists, and the fourth largest identified collaboration of 67.40% is with internal specialists.

> I do feel your group or the government should provide funding as we have none.
>
> - Comment from a Survey participant

From the total number of returned surveys, 62.79% participants chose location as a consideration for establishing their practices. For 18.60% participants, affordability was the choosing factor. Only one (2.32%) participant stated that having wheelchair access was a determining factor. One respondent did not provide an answer.

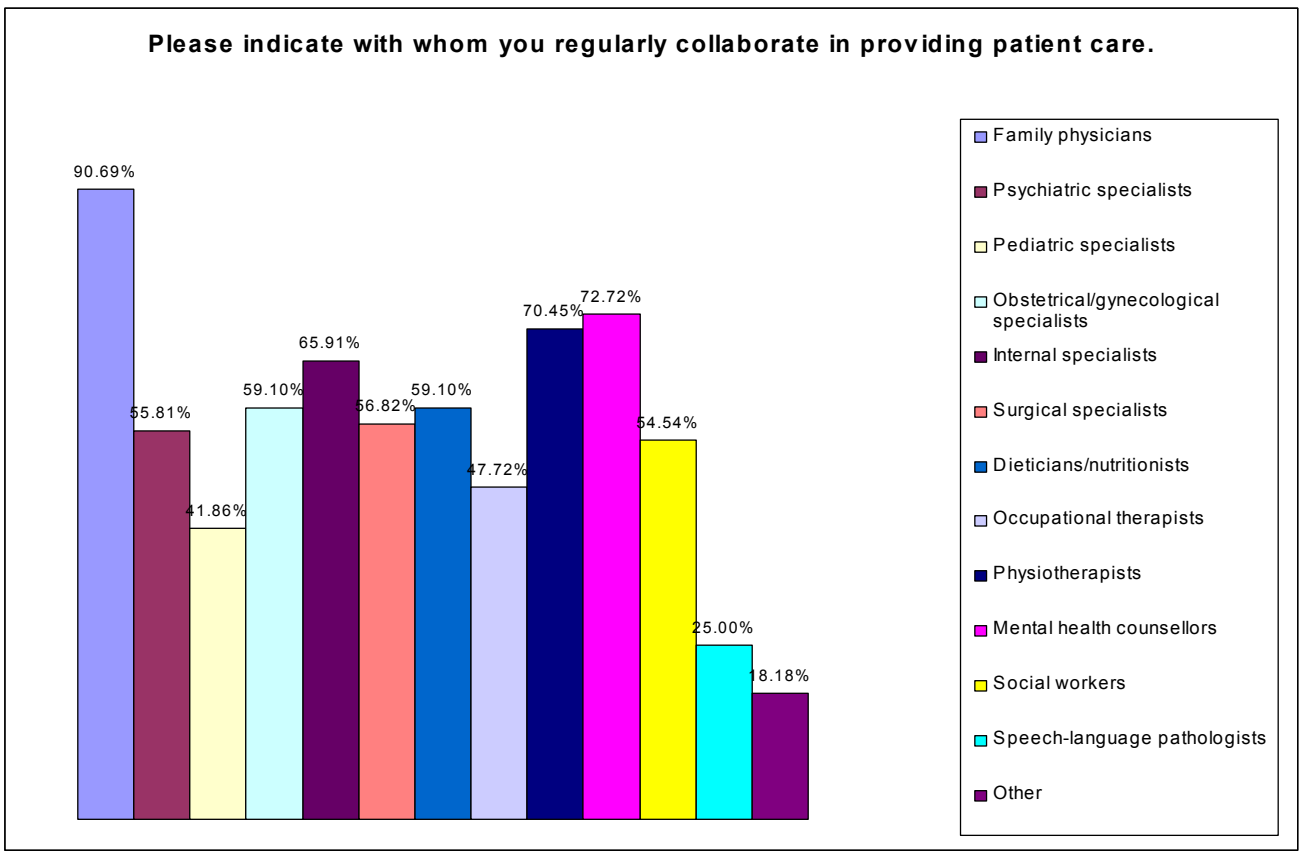


Figure 34: Regular collaborations

From the 44 participants, 18.18% stated under *Other* that in addition to the stated survey choices, they collaborate with nurses, pharmacists, massage therapists, hospitals, and community organizations.

Types of disabilities and number of patients with disabilities

Questions 10 and 11 from the survey enquired about the number of patients and type of disabilities that the survey participants provided services to. As per figure 35, the majority of participants (70.45%) provide services to *More than 21 Patients with Disabilities*. Patients with chronic medical disorders (95.45%), physical impairment (88.63%), and cognitive disorders (88.63%) are the most recurrent.

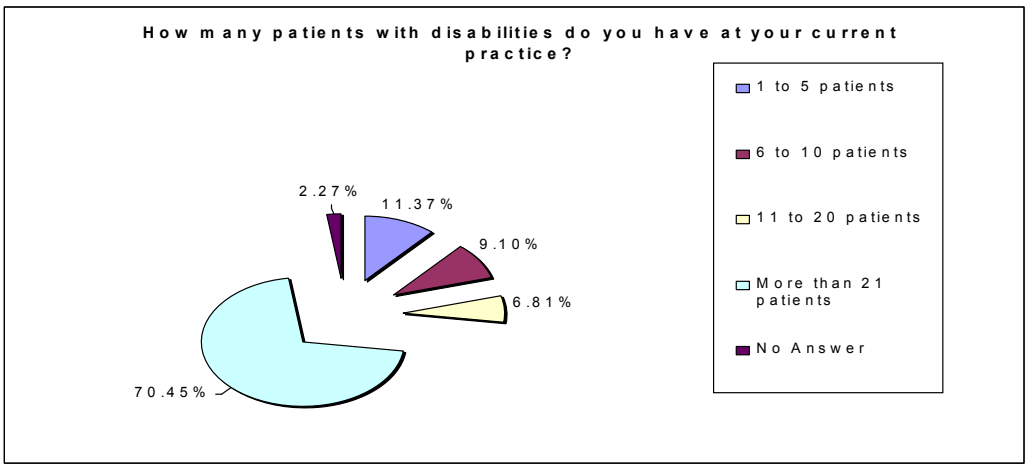


Figure 35: Number of patients with disabilities

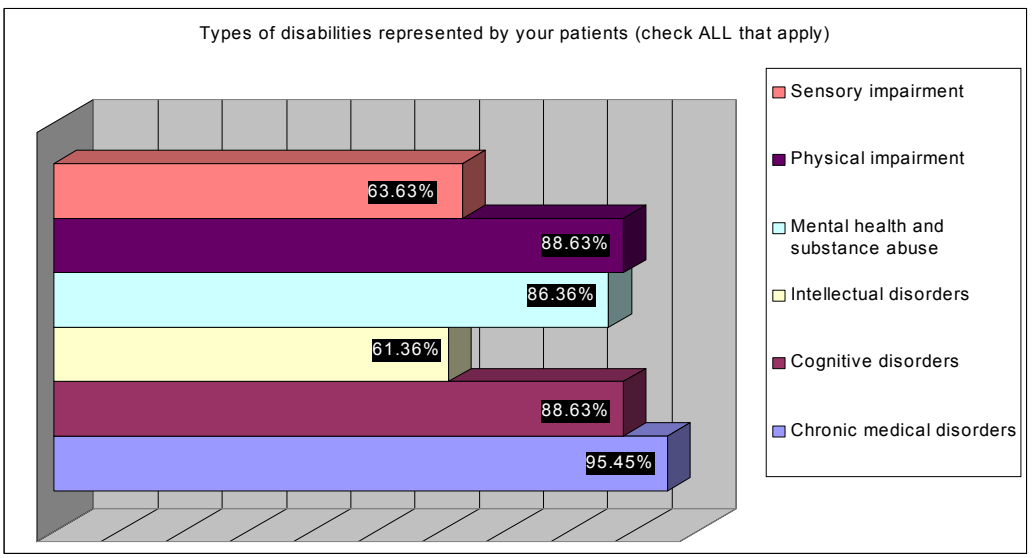


Figure 36: Types of disabilities represented by the patients (multiple answers)

Participants were asked to check all types of disabilities. Only two participants marked one type of disability.

> It is unreasonable for all facilities to be capable of providing access for all classes of disability. Some are too extreme and if patients with extreme disability are referred, advance assessment needs to be done.
>
> - Comment from a survey participant

Physical accessibility, polices, and procedures for people with disabilities

The next set of 35 questions in the Survey asked the participants about physical accessibility outside the clinic, inside the clinic, in the examination room, types of equipment, and availability of certain services that people with disabilities might deem necessary.

Physical Accessibility – Outside the Clinic

Overall, the participants identified accessible access to their clinics. Only two participants identified that there are no clearly marked parking stalls, and five participants acknowledged that there is no appropriate directional signage. More than 50% of the participants identified that there are no power door operators at the entrance of their clinics.

Question	Yes	No	Not Sure	No Answer	Not Applicable
Are there clearly marked accessible parking stalls at your office?	41	2	0	1	0
	93.18%	4.55%	0.00%	2.27%	0.00%
Is there a path of travel that does not require the use of stairs?	38	6	0	0	0
	86.36%	13.64%	0.00%	0.00%	0.00%
If there are stairs, is there a ramp that allows easy access to the entrance?	19	3	1	12	9
	43.19%	6.82%	2.27%	27.27%	20.45%
Are there clearly visible and easily understood signs to indicate the entrance?	38	5	1	0	0
	86.36%	11.37%	2.27%	0.00%	0.00%
Is there a smooth surface transition from the parking to the entrance?	38	4	2	0	0
	86.36%	9.09%	4.55%	0.00%	0.00%
Are there power door operators at the interior and exterior entrances of your office?	21	23	0	0	0
	47.73%	52.27%	0.00%	0.00%	0.00%
Is there enough space for a wheelchair/scooter to use the entrance?	41	1	1	1	0
	93.19%	2.27%	2.27%	2.27%	0.00%

Figure 37: Physical accessibility – outside the clinic

Physical Accessibility – Inside the Clinic

In this part of the Survey, 76.74% of the participants identified that the doors to the clinic are easy to open, and 95.46% stated that the hallways leading to the examining room are wide enough for a wheelchair/scooter to pass. It was identified by 30 participants that their clinics do not have a lower section of counter for people who cannot stand when speaking with the receptionist. Thirty-seven participants identified strong colour contrast between the walls and the doors in their clinic.

Question	Yes	No	Not Sure	No Answer
Is the entrance door to your office easy to open (minimal strength required to open or close)	33	8	3	0
	75.00%	18.18%	6.82%	0.00%
Does the reception area have a lowered section of counter for people who cannot stand when speaking with the receptionist?	11	30	1	2
	25.00%	68.18%	2.27%	4.55%
Can objects protruding from the walls be easily detected by canes used by people with visual impairments?	29	5	9	1
	65.91%	11.36%	20.46%	2.27%
Are the hallways leading to the examining room wide enough for a wheelchair/scooter?	42	1	1	0
	95.46%	2.27%	2.27%	0.00%
Is there visible and easily understood directional signage?	28	12	3	1
	63.64%	27.27%	6.82%	2.27%
Is there strong colour contrast between the doors and walls?	37	5	2	0
	84.09%	11.36%	4.55%	0.00%
Are there enough chairs for use by people who cannot stand while waiting?	42	1	1	0
	95.46%	2.27%	2.27%	0.00%
Is there enough space in the waiting room for people in wheelchairs/scooters to manoeuvre/wait?	40	2	2	0
	90.90%	4.55%	4.55%	0.00%
Is there an accessible washroom with enough space for a wheelchair/scooter to fit and close the door?	39	4	1	0
	88.64%	9.09%	2.27%	0.00%
Is there a washroom sign with Braille or raised letter instructions?	2	34	7	1
	4.55%	77.27%	15.91%	2.27%

Figure 38: Physical accessibility – inside the clinic

Thirty-nine of the Survey participants marked that there is an accessible washroom in their clinics; however, only two of the participants stated that there is a washroom sign with Braille or raised letter instructions available for patients with visual impairments.

The Examination Room

One of the issues identified by people with disabilities is the inappropriate size of the physician's examination rooms. In our Survey, only 15.91% of the participants identified that there is not enough space in the examination room in their clinics for the patient and the staff members to move around comfortably.

Question	Yes	No	Not Sure	No Answer
Is the doorway into the examination room wide enough for a wheelchair/scooter?	39	3	2	0
	88.63%	6.82%	4.55%	0.00%
Are the door handles on the examination room's lever type?	18	23	3	0
	40.91%	52.27%	6.82%	0.00%
Is there enough space in the patient room for you and the staff to move around comfortably?	37	7	0	0
	84.09%	15.91%	0.00%	0.00%
Is there an adjustable examining table or a chair?	25	19	0	0
	56.82%	43.18%	0.00%	0.00%

Figure 39: Accessibility of the examination room

Another participant recognized barrier for people with disabilities is the examination table/chair. Twenty-five participants acknowledged that their clinics are equipped with a height-adjustable examining table or chair.

Available Equipment

It is unsurprising that only a small number of clinics are equipped with equipment that is used by individuals with certain disabilities. Only 9.09% of the participants answered that their clinic has a scale with grab bars for individuals who have difficulty standing. Only 6.82% answered that there is a scale that allows people to be weighed while sitting in a chair. These participants identified that the reason for this availability is because their clinic is situated within a hospital or next to a hospital.

Question	Yes	No	Not Sure	No Answer
Is there a scale with grab bars in your office for people who have difficulty standing?	4	39	1	0
	9.09%	88.64%	2.27%	0.00%
Is there a scale that allows people to be weighed while sitting in a wheelchair?	3	38	3	0
	6.82%	86.36%	6.82%	0.00%
Is there a scale that is attached to a sling lift so than an individual can be lifted and weighed?	4	39	1	0
	9.09%	88.64%	2.27%	0.00%
Is there a scale for people who weigh in excess of 350 lbs (158.75 kg)?	7	32	5	0
	15.91%	72.72%	11.37%	0.00%
Is there an amplified communication system or device with volume control at the reception desk?	3	34	5	2
	6.82%	77.27%	11.36%	4.55%
Is there a TTY phone at your office in order to contact patients with hearing impairments?	2	34	7	1
	4.55%	77.27%	15.91%	2.27%
Are the staff knowledgeable in using a TTY phone when contacting patients with hearing impairments?	2	28	12	2
	4.55%	63.63%	27.27%	4.55%

Figure 40: Medical equipment

In addition, only 4.55% of the participants marked that there is a phone equipped with relay service available in their office with the purpose of contacting individuals with hearing impairments.

Provision of Services

In the survey, we asked the participants about assistance being offered to patients with disabilities when moving from the mobility device to the examination table, and 15 responded that the staff arranges a transfer team. Nineteen participants checked that there is assistance throughout procedures to move people with disabilities from one apparatus to another, and 75.00% identified that there is assistance available for individuals with disabilities to undress and dress.

Question	Yes	No	Not Sure	No Answer
Do the staff arrange to have a transfer team to assist people with physical impairments when moving from the mobility device/wheelchair/scooter to the table?	15	28	1	0
	34.10%	63.63%	2.27%	0.00%
Is there assistance throughout procedures to move people with disabilities from one apparatus to another?	19	16	5	4
	43.19%	36.36%	11.36%	9.09%
Is there assistance for people with disabilities to undress/dress?	33	8	2	1
	75.00%	18.18%	4.55%	2.27%
If needed, do the staff arrange for sign language interpreters in advance?	6	29	5	4
	13.63%	65.91%	11.37%	9.09%
Are alternate formats of communication provided?	16	20	7	1
	36.37%	45.45%	15.91%	2.27%
Is informational material available in various formats (Braille) at your office?	1	36	6	1
	2.27%	81.83%	13.63%	2.27%
Does your office accommodate various disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?	23	16	3	2
	52.27%	36.36%	6.82%	4.55%

Figure 41: Provision of services

Twenty participants stated that their patients are able to receive alternative forms of communication; but only one participant stated that information is available in various formats at their office.

From the 44 survey participants, 52.27% identified that their office accommodated various disability needs when needing to access an interpreter, other forms of communication, or extra appointment times.

When you prescribe a test like a mammogram or a CT scan, how do you assure that the location has accessible imaging devices?

In this open-ended question, participants were asked about assuring accessibility to locations outside of their practice when prescribing tests that use imaging devices. Many stated, "I just assume that they are accessible"[308] or "I assume the location has accessible imaging devices." Some pointed out that the "booking clerk tells them," or "did not know this was possible" or "we have limited resources and make do with what we have currently." Fourteen participants wrote that they did not know what can be done.

> "Many patients cannot have diagnostic tests (including MRI, CT) due to obesity or immobility."
>
> - Comment from a survey participant

My office has everything needed to provide patients with disabilities with complete medical care.

The next set of questions, asked the participants if they feel that their practice is set up to provide complete medical care to patients with disabilities. From our respondents, 43.18% stated *Strongly Agree* or *Agree* with the statement. 31.82% identified with *Disagree* and *Strongly Disagree*. 25.00% were *Uncertain* if their practice can provide complete medical care to people with disabilities.

[308] These statements are verbatim.

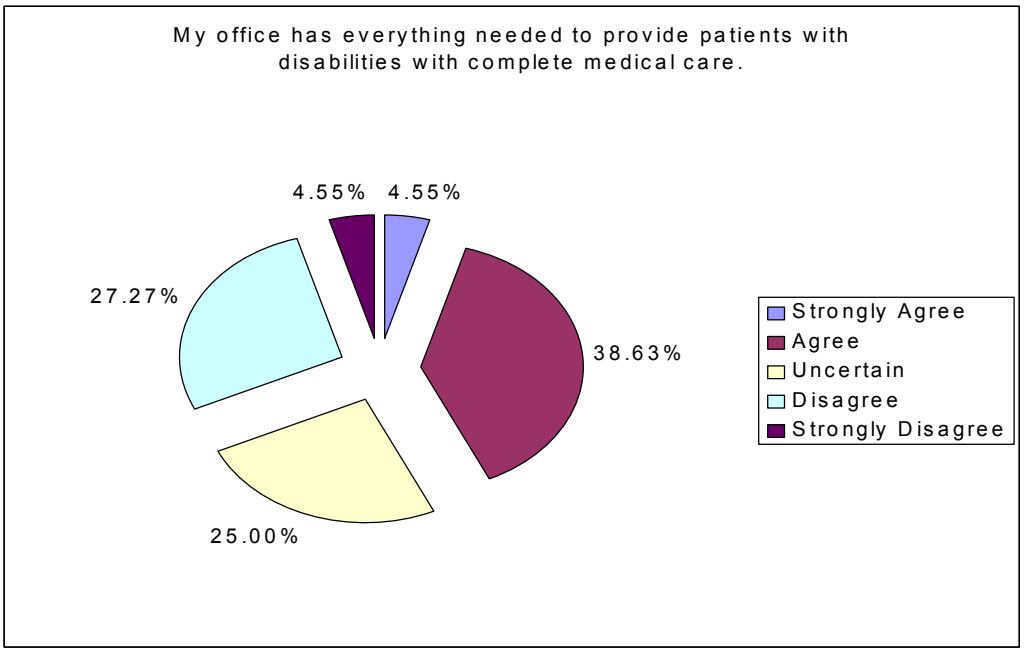


Figure 42: My office has everything needed to provide patients with disabilities with complete medical care

Does your practice have a process to identify the needs of patients with disabilities?

One of the goals of the Survey was to identify processes of how health and medical professionals respond to the needs of patients with disabilities. From the received responses, 31.81% stated that they have processes in place as "multidisciplinary team doing initial assessments," "questioning, history, exam," "alerts on charts," "as the physician gets to know the patient they will identify these needs,"

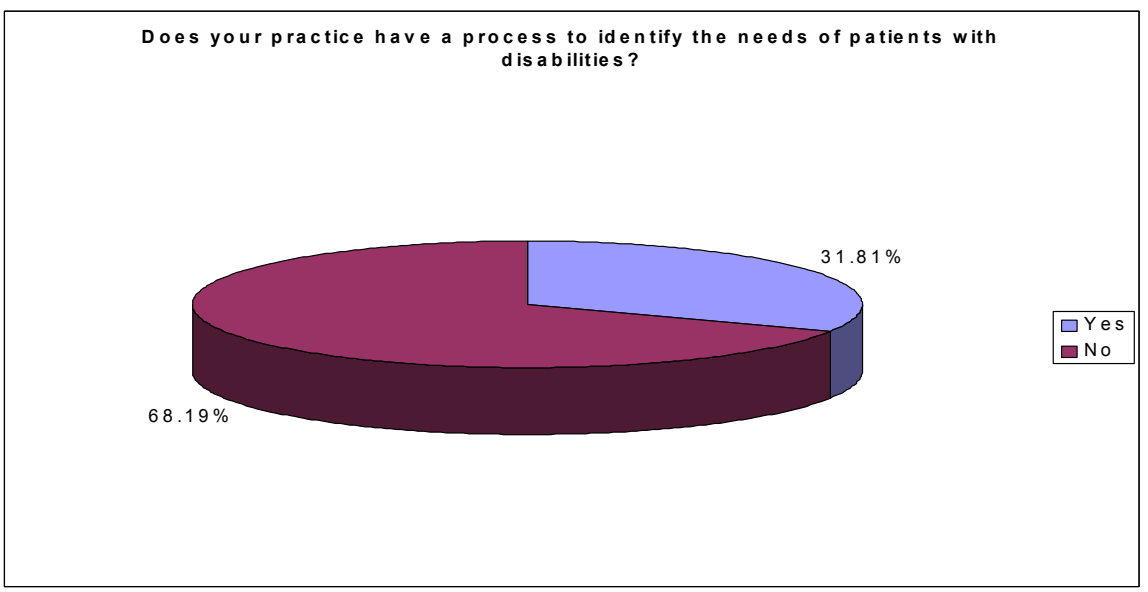


Figure 43: Does your practice have a process to identify the needs of patients with disabilities?

"visual inspection," "triage screening, "and "PT, OT and nursing assessments on each new patient." One Survey participant stated because the medical practice is in a small rural area, physicians have a good understanding of the needs of their patients.

68.19% stated that their medical clinic does not have processes set in place to identify the needs of patients with disabilities. These Survey participants stated that even though they do not have processes in place, they rely on their ability to assess patients and provide appropriate medical care.

Do you have policies and procedures for managing patients with disabilities?

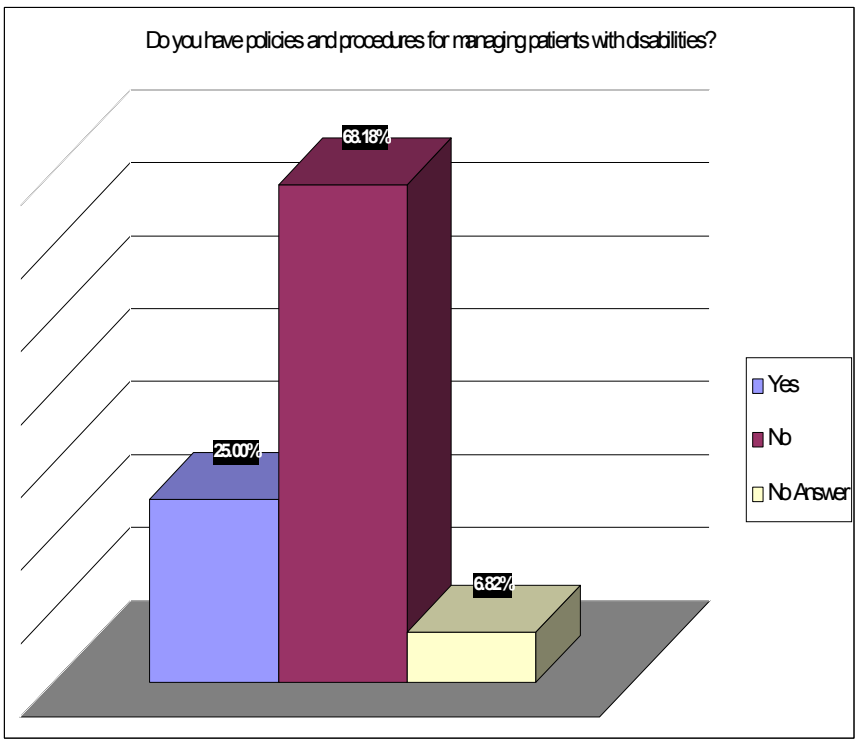


Figure 44: Do you have policies and procedures for managing patients with disabilities?

ACCD enquired about polices and procedures for managing patients with disabilities. Thirty Survey participants marked *No* as the answer. Reasons for lack of written policies and procedures, "if help is needed with disabled people we call for nursing support," "multidisciplinary team does initial assessments," "staff identify and assist all patients with disabilities," "triage nurse, hospital protocols," and "a small office."

> There must be some responsibility on the part of the disabled to make their needs and expectations known before the visit.
>
> - Comment from a Survey participant

Do you offer training to your support staff in how to work and assist people with disabilities?

The purpose of the question was to identify the training available to staff for working and assisting people with disabilities. The majority of Survey participants answered that they do not provide training because "we have RNs on site who supply expertise," "knowledgeable staff train new staff," and "staff aware of what to explain on the phone and to help when in clinic."

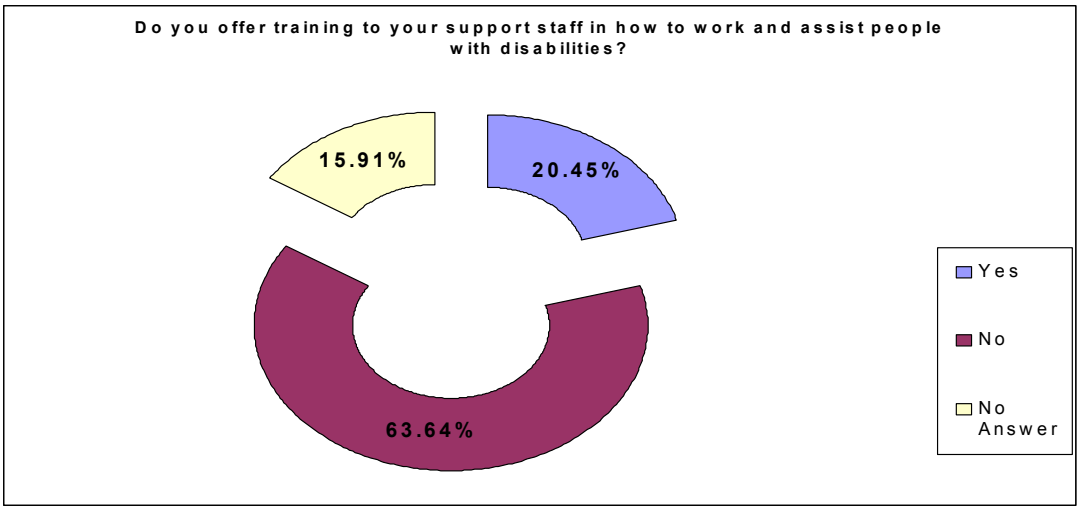
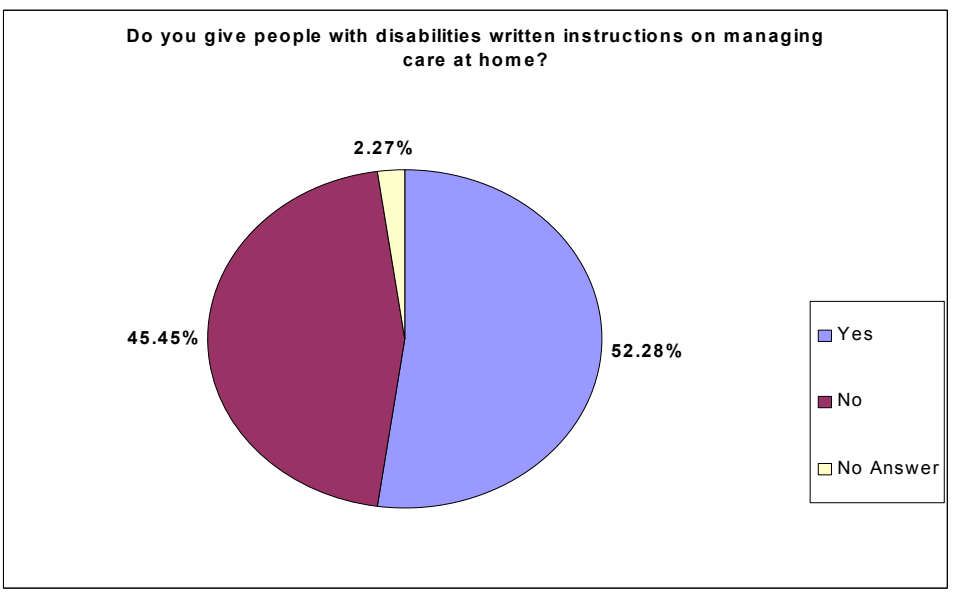


Figure 45: Do you offer training to your support staff in how to work and assist people with disabilities?

The nine participants that checked *Yes*, provided the following explanations: "hospital and nursing home staff have ongoing educational sessions," "part of orientation and ongoing education," "regular monthly in-service," and "in clinic training."

Do you give people with disabilities written instructions on managing care at home?



One of the challenges that people with disabilities face is the ability to receive information in a manner that is understandable and easy to follow.

Figure 46: Do you give people with disabilities written instructions on managing care at home?

We asked the health professionals if they give written instructions for managing care at home. The results were 52.28% give written instructions, and 45.45% do not provide this service.

We followed up with the question by asking how long it takes to provide this service for the ones that checked *Yes*. The average time allocated to provide written instructions was between 15 to 20 minutes per patient. One participant stated that they need a half hour to an hour on certain occasions to provide this service.

The next question enquired if the survey participants routinely give their patients a written list of all medications, and 59.09% marked *No*.

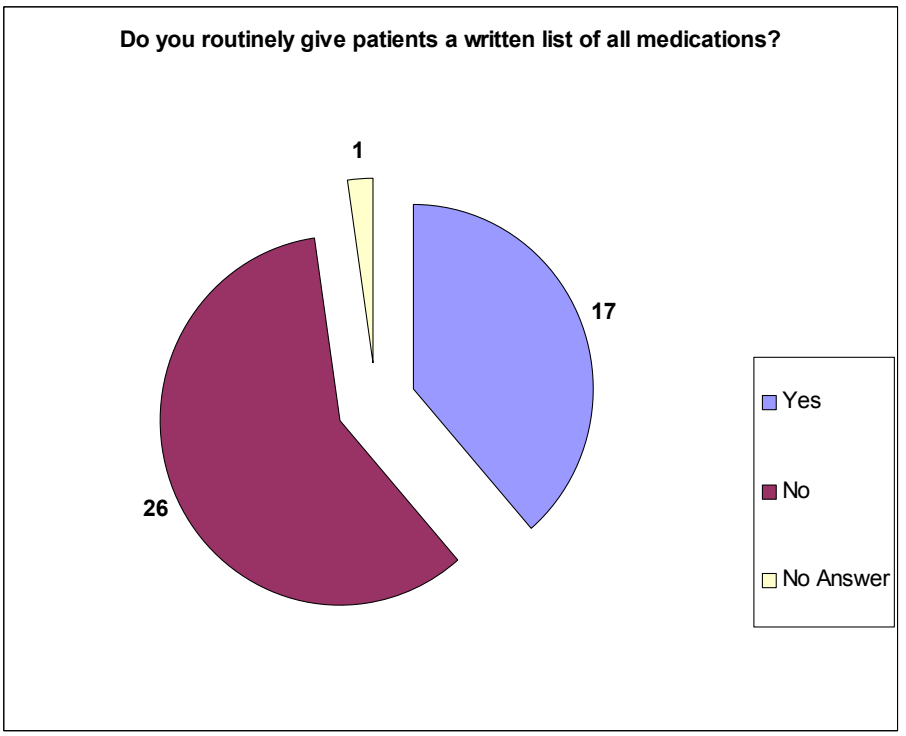


Figure 47: Do you routinely give patients a written list of all medications?

How would you rate your personal satisfaction with your practice?

On the subject concerning personal satisfaction with the practice, only one participant marked *Poor.* All other survey participants marked *Good* or *Excellent*.

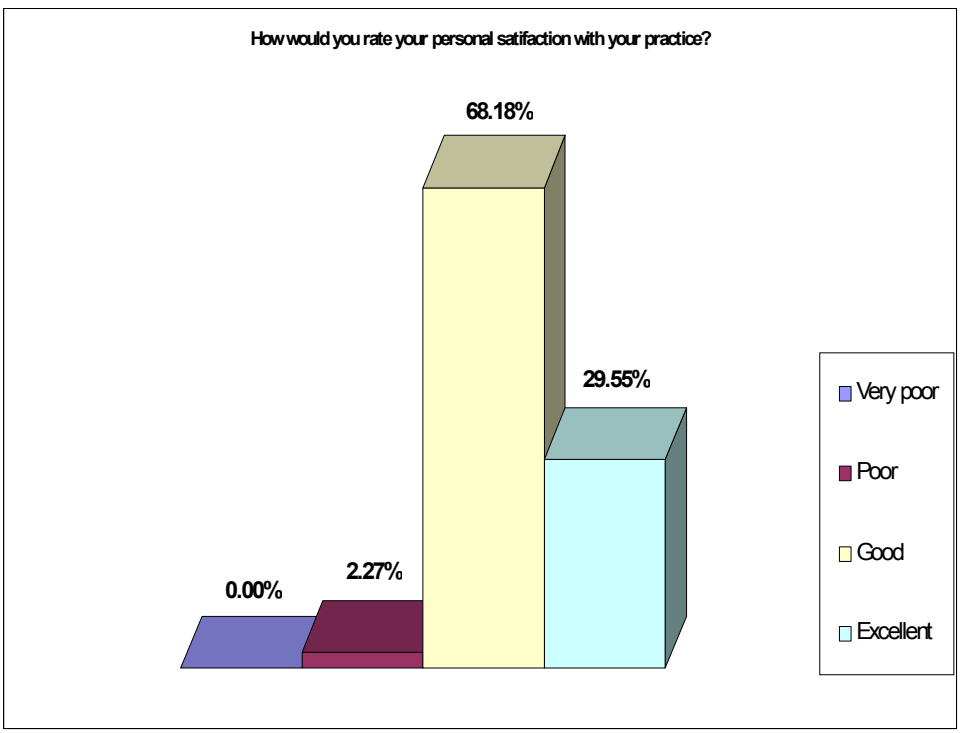


Figure 48: Personal satisfaction with the practice

View on the current health system

From the 44 Survey participants, 56.82% believe that the health care system in Alberta needs fundamental changes in order to improve services not only for people with disabilities but all Albertans. 9.09% marked that the health care system needs to be completely rebuilt, and 22.73% stated only minor changes are needed.

> Unsure of available help
>
> - Comment from a survey participant

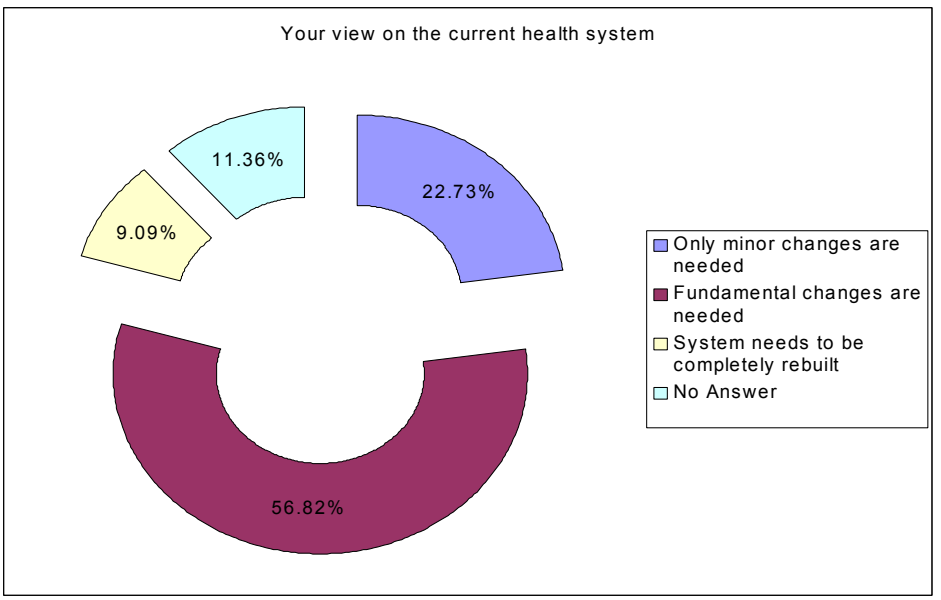


Figure 49: View of the current health care system

What do you see as a major barrier to providing care to people with disabilities?

> 1. Financial problems - it's expensive to modify offices;
> 2. Time Constraints - lots of people needing to be seen, so each patient gets less time
>
> - Comment from a survey participant

In this open-ended question, we asked what the major barriers are that health professionals see when providing care to people with disabilities. For some it was that there are "No incentives to make changes to current practice; little time to make changes due to patient load and burnout," "lack of government acknowledgement or the will to change," "funding for facilities like medical offices that are 'private' businesses," "all procedures/mechanisms are expensive," or "government politics/lack of time/many forms to fill in."

For others "it is unreasonable for all facilities to be capable of providing access for all classes of disability. Some are too extreme and if patients with extreme disabilities are referred advance assessment needs to be done."

One participant stated that "people have a narrow view of disability and are often unwilling to make modifications, need to make more people aware, and greater advocacy." The critical importance of having enough time was also acknowledged.

> "Time - these patients require more time than others. They also need extra nursing help. It seems other patients suffer at their expense due to their need for more time,"

and

"They take more time in the office which used to be a loss of income for the doctor and the clinic. The new formulas reorganizing time have helped with this."

Participants stated that often landlords do not allow physical modifications and accessible equipment, settings are very costly, and there are no government funds that can assist with this need.

First task is to de-stigmatise disability, talk about it, and accept it.
- Comment from a survey participant

What would you like to see improved immediately regarding barrier-free access to medical clinics and diagnostic tests for people with disabilities?

The final question in the Survey was to see what health professionals need to have in order to improve service provision to patients with disabilities. Many of the answers were associated with funds and responsibilities:

"We have building laws, sidewalk laws already. Where are you coming from with this? Are you fundraising to help the health providers provide more than is already in place? Good for you if you got a grant! We are getting funds frozen, eliminated or clawed back to provide what your group wants."

"Consider that resources for people with disabilities are very costly yet they only constitute a minority of all patients, and most other patients do not need them and all costs may not be financially/statistically justifiable unless a clinic is specifically dedicated to managing disorders."

"Lack of time to appropriately assess and manage complex issues/situations; my ignorance of how to access community resources."

It was stated that policymakers do not understand the needs of physicians or patients:

Lack of government acknowledgement or the will to change this; inadequate funding
- Comment from a survey participant

"For example, distant based administrators who never come to 'walk a mile in the other guy's boots', who make decisions without consulting the people who do the job, and who are seldom available when help is needed, e.g. 'I am not at my desk at the present, please leave a message..."

"Governmental intervention, i.e. have specialists in this area examine site and arrange for accommodation. I do feel your group or the government should provide funding as we have none."

Conclusion

"No incentive to make changes to current practice."
- Comment from a survey participant

The statements above clearly show that there is a need for improvement in accessible services for people with disabilities, but programs and services restructuring and the decrease in funding opportunities, provide no alternative options for physicians but to provide health services based on the limited resources available to them. The recurring question is "who will pay for any changes," and this issue needs to be addressed before the health care system is able to accommodate and provide services to all Albertans who are in need of medical and health services.

Survey Results for People with Disabilities: Summary of the Findings

Introduction

For the purpose of identifying barriers to health and medical services for people with disabilities, a survey was designed to gather information about perceived and experienced barriers. The survey was released through Survey Monkey (http://www.surveymonkey.com/) on April 14, 2010, with June 30, 2010, as the deadline for input.

Sample Selection

The target population for the survey was people with disabilities[309]. This population was targeted via e-mail, newsletters, and community consultations. In addition, a press release was disseminated on April 26, 2010, to inform the public about the survey and the community consultations. Our method was chain sampling as we relied on people with disabilities or those who know people with disabilities to complete the survey. Because of this method of sampling, we could not provide a reliable return rate. The sample is not representative of the population because we did not have control over who filled out the questionnaires; conversely, the broad promotion ensured a sample of individuals with various disabilities.

Data Collection

ACCD collected classifying data such as age, location, employment, disability/disabilities, living settings, and care. In addition, data was collected to identify the perceived barriers and desired solutions when accessing health and medical services. By June 30, 2010, 464 individuals had filled out the survey; however, only 335 individuals (72.2%) answered all the questions.

The following categories were addressed in the survey:

- General information
- You, as the user of services
- Accessing health and medical services in Alberta
- The service
- The need for change

Survey participants were asked to state their disability/disabilities and the following categories were identified:

[309] The survey was filled out by a guardian or a family member on behalf of the individual.

Disability Category Classification[310]	Number of Identified Participants	Percentage of Identified Participants
Hearing	22	4.74%
Seeing	8	1.72%
Speech	1	0.22%
Pain	41	8.84%
Learning	20	4.31%
Mobility and Agility	171	36.85%
Memory	2	0.43%
Developmental	18	3.88%
Psychological (mental)	14	3.02%
Multiple	73	15.73%
None	94	20.26%
TOTAL	**464**	**100.00%**

Figure 50: Disability Category Classification

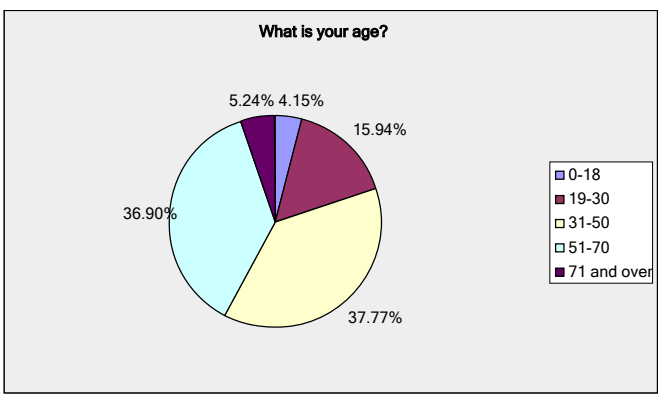
The survey produced quantitative and non-quantitative data. Participants were asked to answer only the questions that related to them personally, and the answers reflect the unique needs of individuals with varying disabilities.

The calculated percentages are from the total number of answered questions, without including the number of skipped questions in the equation.

The following sections demonstrate the findings from the survey for people with disabilities.

General Information

Age



From the survey participants, the largest majority (74.67%) were individuals between the ages of 31 to 70 years old. Although, the survey targeted individuals 18 and over, nineteen individuals under the age of 18 filled out the survey. Six individuals skipped this question.

Figure 51: Age of survey participants

[310] Human Resources and Skills Development Canada. *Indicators of Well-being in Canada: Canadians in Context – People with Disabilities.* Retrieved on July 25, 2010, from http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=40.

Disability	0-18	19-30	31-50	51-70	71 and over	Skipped Question
Hearing	1	3	10	7	1	0
	0.22%	0.65%	2.18%	1.53%	0.22%	
Seeing	0	2	2	3	1	0
	0.00%	0.43%	0.43%	0.65%	0.22%	
Speech	0	0	1	0	0	0
	0.00%	0.00%	0.22%	0.00%	0.00%	
Pain	0	1	17	22	1	0
	0.00%	0.22%	3.71%	4.80%	0.22%	
Learning	1	14	2	3	0	0
	0.22%	3.06%	0.43%	0.65%	0.00%	
Mobility and Agility	8	20	67	63	12	1
	1.74%	4.37%	14.63%	13.76%	2.62%	
Memory	0	0	1	0	1	0
	0.00%	0.00%	0.22%	0.00%	0.22%	
Developmental	2	3	8	5	0	0
	0.43%	0.65%	1.75%	1.10%	0.00%	
Psychological (Mental)	1	5	5	3	0	0
	0.22%	1.10%	1.10%	0.65%	0.00%	
Multiple	5	10	31	25	2	0
	1.10%	2.18%	6.77%	5.46%	0.43%	
None	1	15	29	38	6	5
	0.22%	3.28%	6.33%	8.30%	1.31%	
					answered question	**458**
					skipped question	**6**

Figure 52: Age of survey participants according to disability classification

Gender

On the question, *What is your gender?*, 132 (28.81%) individuals answered male and 326 (71.19%) female.

Disability	Male	Female	Skipped Question
Hearing	3	19	0
	0.65%	4.15%	
Seeing	4	4	0
	0.87%	0.87%	
Speech	0	1	0
	0.00%	0.22%	
Pain	6	35	0
	1.31%	7.64%	
Learning	6	13	1
	1.31%	2.84%	
Mobility and Agility	64	107	0
	13.97%	23.37%	
Memory	1	1	0
	0.22%	0.22%	
Developmental	7	11	0
	1.53%	2.40%	
Psychological (Mental)	2	12	0
	0.43%	2.62%	
Multiple	19	54	0
	4.15%	11.80%	
None	20	69	5
	4.37%	15.06%	
		answered question	**458**
		skipped question	**6**

Figure 53: Gender of survey participants according to disability classification

Location of Participants

The survey was filled out by 464 Albertans, of which 435 provided information about the location of their residences. From the 435 participants, 326 (74.94%) were from urban locations, 108 (24.83%) from rural locations in Alberta and one participant (0.23%) identified location as a reserve. The following map shows the distribution of survey participants throughout the province:

Figure 54: Participants locations of residence

The survey participants represent 56 identified locations in Alberta.

Three individuals identified their residences in Whitehorse, San Antonio, and Toronto, even though the project targeted residents of Alberta, which was clearly identified in the preamble to the survey.

Although, extensive promotion of the survey was conducted, we were not able to reach individuals in the High Level/Fort Vermillion/Fort Chipewyan area. The ACCD team contacted Family and Community Support Services in those areas, but with no success. A complete list of the locations is included in Appendix IV.

The following chart illustrates the residence locations according to the disability categories:

Disability	Urban	Rural	Skipped Question
Hearing	19	2	1
	4.50%	0.47%	
Seeing	6	2	0
	1.42%	0.47%	
Speech	0	1	0
	0.00%	0.24%	
Pain	28	9	4
	6.63%	2.13%	
Learning	17	1	2
	4.06%	0.24%	
Mobility and Agility	128	37	6
	30.33%	8.77%	
Memory	2	0	0
	0.47%	0.00%	
Developmental	7	9	2
	1.66%	2.13%	
Psychological (Mental)	12	2	0
	2.84%	0.47%	
Multiple	57	12	4
	13.50%	2.84%	
None	50	21	23
	11.85%	4.98%	
answered question			422
skipped question			42

Figure 55: Residence locations according to the disability classification

Living Setting

The survey enquired about the living settings of the participants. Out of the 406 participants who answered the question, 76.11% (309) live independently, 12.07% (49) marked various other explanations such as currently no permanent residence or sleeping on someone's sofa, 10.10% (41) reside in supportive living, 0.74% (3) reside in a lodge, and 0.98% (4) reside in a long term care facility.[311]

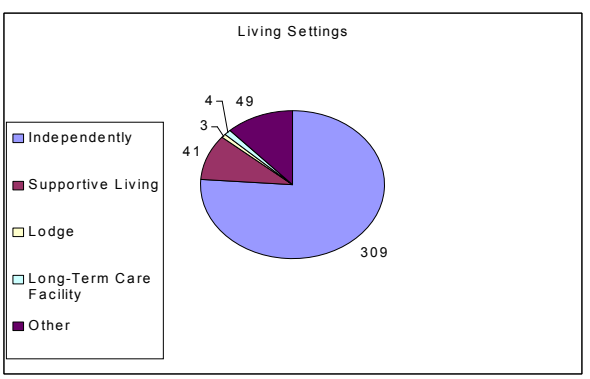


Figure 56: Living settings

[311] A break down by disability category and living settings is included in Appendix IV.

My household is unique in that we have three disabled people living together; husband and wife and a roommate; without the support of the other people in the house, I would not be able to live independently. - *Comment from a survey participant*

Identified Disabilities

The question about what are the disability/disabilities of the survey participants was an open-ended question. Individuals were asked to explain and state their disability/disabilities. The following list states the various disabilities represented in our survey sample:

- Acute Disseminated Encephalomyelitis
- ADHD/ADD
- Amputee
- Aneurisms
- Ankylosing Spondylitis
- Arthritis
- ArthroGryposis
- Asperger Syndrome
- Asthma
- Autism
- Bi-Polar
- Blind
- Brain Injury
- Cancer
- Central Core Disease
- Cerebral Palsy
- Chromosome Abnormality
- Chronic Pain
- Coccydynia
- Cognitive
- Colitis
- Colostomy
- Crohn's Disease
- Deaf
- Degenerative Disc Disease
- Depression
- Developmental
- Diabetes
- Dissociative Disorder
- Down Syndrome
- Dysthymia
- Edema
- Epilepsy
- Fetal Alcohol Syndrome Disorder
- Fibromyalgia
- Generalized Anxiety Disorder
- Hard of Hearing
- Heart Stroke
- Hemiplegia
- Hyperacusis
- Hypoglycemia
- Immune Deficiency
- Learning Disability
- Lupus
- Lyme Disease
- Memory
- Metal Health
- Multiple Chemical Sensitivities
- Multiple Sclerosis
- Myotonic Dystrophy
- Obesity
- Organic Affective Disorder
- Osteoporosis
- Peripheral Neuropathy
- Polio
- Polycystic Liver Disorder
- Polymyalgia Rheumatica
- Post-Traumatic Stress Syndrome
- Raynaud's Phenomenon
- Retinopathy
- Scoliosis
- Severe Global Developmental Delay
- Sleeping Disorder
- Speech Impaired
- Spina Bifida
- Spinal Cord Injury
- Voice Disorder

In order to correlate findings and provide recommendations, all declared disabilities were grouped in the following categories:

- Hearing: individuals that identified that they are Deaf, hard of hearing or hearing impaired.
- Seeing: individuals that identified Blind, visually impaired or eyesight issues.
- Speech: individuals that identified voice disorders or speech impairments.
- Pain: individuals that identified chronic pain conditions.
- Learning: individuals that identified learning disabilities.
- Mobility and Agility: individuals that identified mobility issues caused by injury or degenerative disease.
- Memory: individuals that identified memory issues.
- Developmental: individuals that identified developmental disabilities.
- Psychological (mental): individuals that identified mental health conditions.
- Multiple Disabilities: individuals that identified more than one disability.
- None: individuals that declared *None*.

The category *None* is to some extent an anomaly because even though individuals wrote *None* as their answer, they answered some questions as if they have a disability. In addition, numerous participants in this category did not answer many of the questions. More comprehensive information relating to each disability group will be presented in the next section of the paper.

Employment Status

> Would like to work however one or all disabilities affect my job performance. Also have found employers not willing to give me a chance. - *Comment from a survey participant*

From the 464 participants, 434 answered the question about employment status, and the highest declared options were 42.62% (185) as employed and 25.11% (109) as unable to work because of a disability.

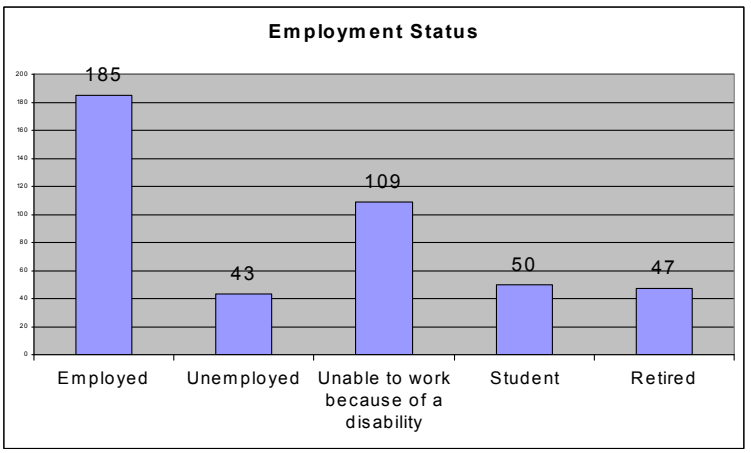


Figure 57: Employment status

> Fact that don't drive and have MS and don't live in city makes employment difficult. - *Comment from a survey participant*

Household Income

This question was answered by 405 survey participants. The largest majority (48.39%) declared that their income is less than $39,999 a year.

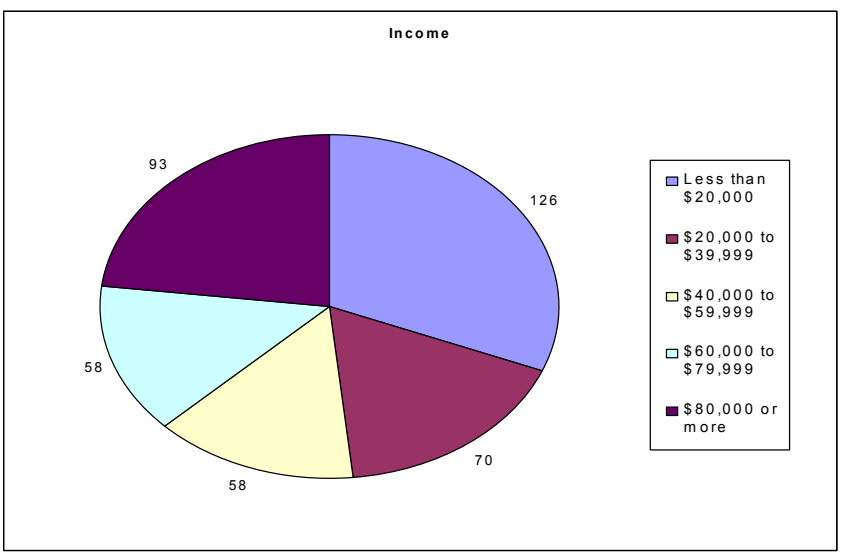


Figure 58: Income

The following charts show the income levels according to disability category:

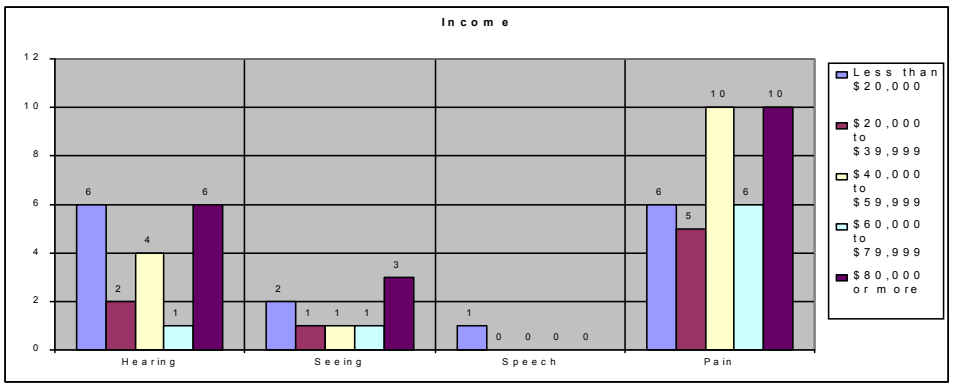


Figure 59: Income according to disability classification (hearing, seeing, speech, and pain)

> It's tough with no income. Mental disabilities receive less attention. - *Comment from a survey participant*

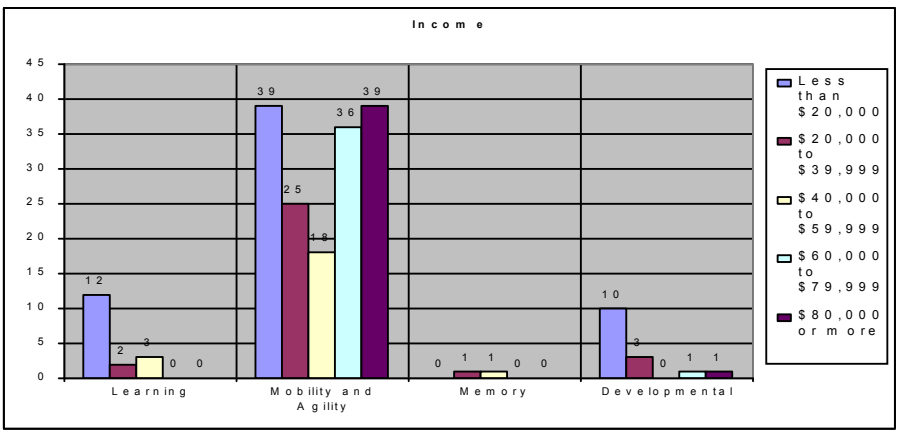


Figure 60: Income according to disability classification (learning, mobility and agility, memory, developmental)

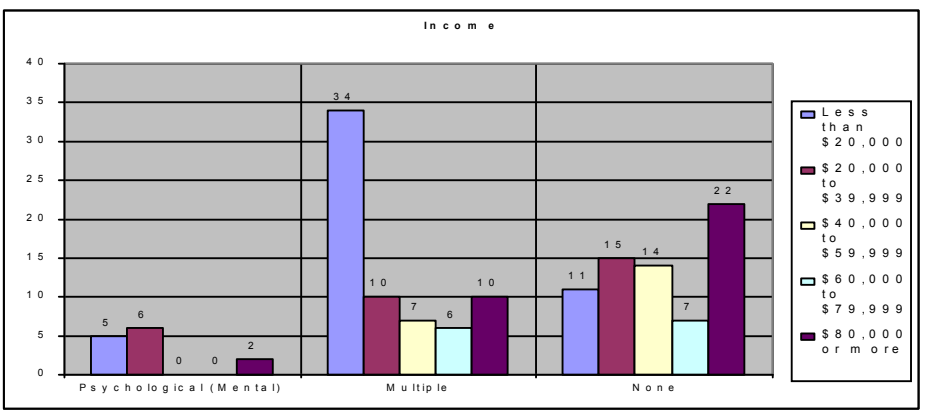


Figure 61: Income according to disability classification (psychological (mental), multiple, none

The charts show that the highest number of individuals who declared income of less than $20,000 a year, are individuals with mobility and agility issues and multiple disabilities.

> I cannot comment because it is private... I suffered by this system. - *Comment from a survey participant*

Source of Support

The purpose of this question was to establish an understanding of the care and support system that is required by some people with disabilities. This question was answered by 429 participants, and the majority of participants identified multiple sources of support. From the 429 participants, 63.17% declared themselves as a source of support. Many who answered *Myself*, also added checked *Family* as their additional source of support.

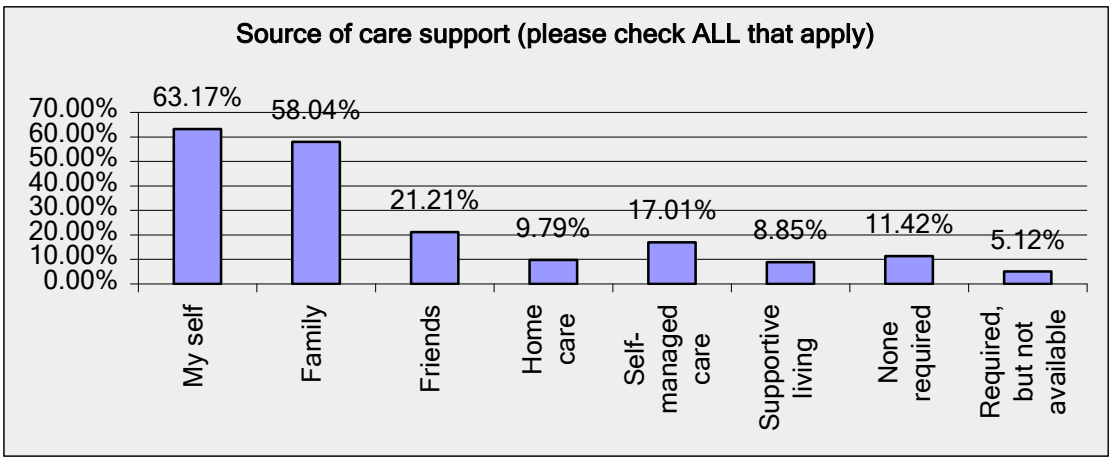


Figure 62: Source of care support

> My husband is becoming worn out from all the extra duties involved in caring for a sick wife. Household chores such as cleaning, cooking, and shopping fall largely to him. He must drive me to all medical appointments (and there are many) because I can't drive. It is very hard for us to learn what kind of support might be available. It seems many of the disabled services are fractured into organizations that don't include me. - *Comment from a survey participant*

A few respondents that marked *Required, but not available* stated that their support systems that were built on family and friends are declining, and they are not able to find ways to renew the supports. Some stated that, even though their physicians recommend more therapy sessions, due to the lack of staff, they are not able to receive the supports they need.

> We are trying to find appropriate care that covers our situation. Not many people are available in Cochrane, my husband's work hours vary (usually evening and weekend) and it's harder to get help in these hours. We have special needs child that needs car. - *Comment from a survey participant*

Health and Well-Being

This question was answered by 442 survey participants, and 60.20% declared that their health and well-being is between good to excellent.

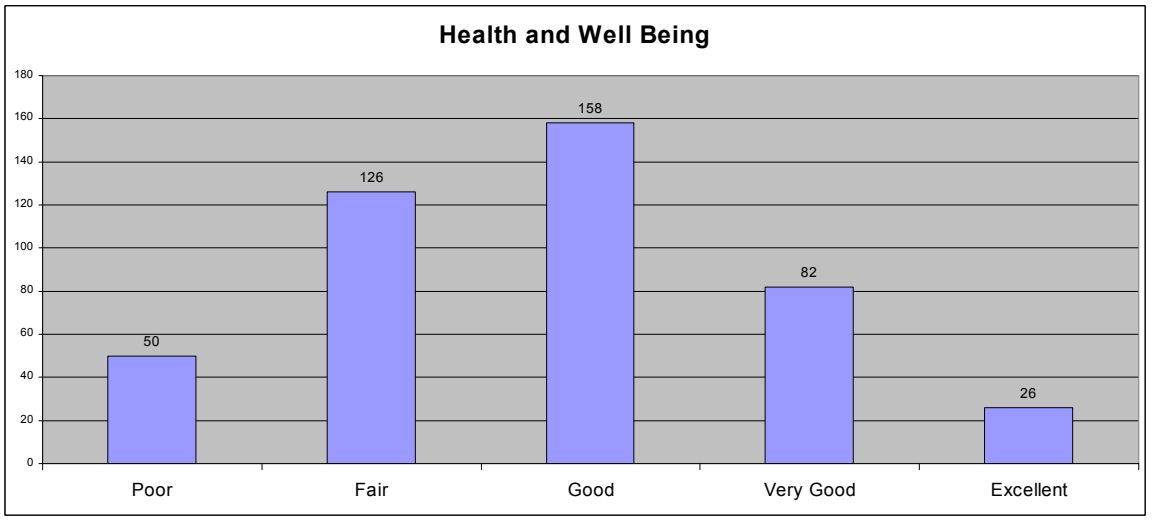


Figure 63: Self-described health and well being

Fifty individuals with multiple disabilities identified with *Poor* or *Fair* health and well being. In addition, 57 individuals with mobility and agility issues identified with *Fair*.

You, as the user of services

The following sets of questions enquire about people with disabilities as patients and how they access services.

Having a Regular Doctor

From 388 participants (76 skipped this question), 56.70% (220) stated that they have a regular doctor who is familiar with their disability. Twenty-seven marked *Regular doctor (general practitioner) who is familiar with my disability but who is reluctant to help me have my needs met*.

Regular doctor (general practitioner) who is not familiar with my disability but is willing to work with me to help me have my needs met was the choice answer of 15.98% (62) participants.

> I have a GP who is not familiar with my disability and speaks about me to my parents even though I am in the room. - *Comment from a survey participant*

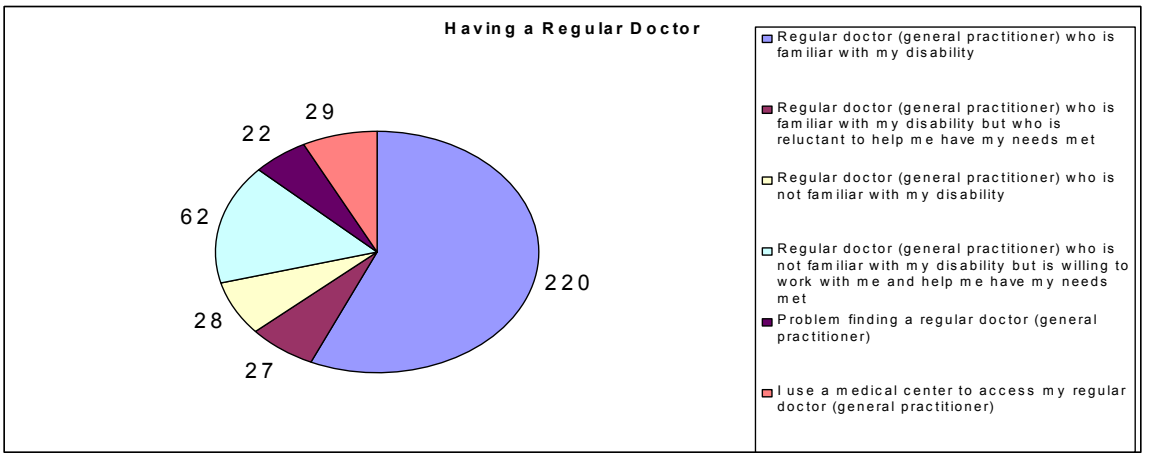


Figure 64: Having a regular doctor

Twenty two (5.67%) individuals declared they have a *Problem finding a regular doctor* and 29 (7.47%) individuals use medical centers to access health and medical services.

> My doctor is reluctant to help because of the ethics governing his profession, the so-so called cost of the diagnostic procedure, the lack of necessary diagnostic equipment, and the indifferent procedure to treat the diagnosed problem for my disability. - *Comment from a survey participant*

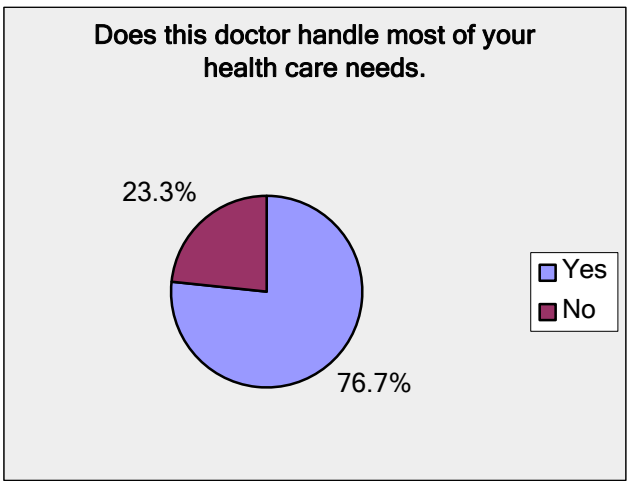
The following chart shows the breakdown according to each disability category:

Disability	Regular doctor (general practitioner) who is familiar with my disability	Regular doctor (general practitioner) who is familiar with my disability but who is reluctant to help me have my needs met	Regular doctor (general practitioner) who is not familiar with my disability	Regular doctor (general practitioner) who is not familiar with my disability but is willing to work with me and help me have my needs met	Problem finding a regular doctor (general practitioner)	I use a medical center to access my regular doctor (general practitioner)	Skipped Question
Hearing	17	0	2	0	0	0	3
	4.38%	0.00%	0.52%	0.00%	0.00%	0.00%	
Seeing	5	0	1	0	0	0	2
	1.29%	0.00%	0.26%	0.00%	0.00%	0.00%	
Speech	0	1	0	0	0	0	0
	0.00%	0.26%	0.00%	0.00%	0.00%	0.00%	
Pain	11	8	3	7	3	2	7
	2.84%	2.06%	0.77%	1.80%	0.77%	0.52%	
Learning	8	0	4	1	4	1	2
	2.06%	0.00%	1.03%	0.26%	1.03%	0.26%	
Mobility and Agility	102	9	8	35	3	6	8
	26.29%	2.32%	2.06%	9.02%	0.77%	1.54%	
Memory	1	0	1	0	0	0	0
	0.26%	0.00%	0.26%	0.00%	0.00%	0.00%	
Developmental	12	1	0	1	1	2	1
	3.10%	0.26%	0.00%	0.26%	0.26%	0.52%	
Psychological (Mental)	6	0	3	3	1	0	1
	1.54%	0.00%	0.77%	0.77%	0.26%	0.00%	
Multiple	38	7	5	12	3	4	4
	9.79%	1.80%	1.29%	3.10%	0.77%	1.03%	
None	20	1	1	3	7	14	48
	5.15%	0.26%	0.26%	0.77%	1.80%	3.61%	
						answered question	388
						skipped question	76

Figure 65: Finding a regular doctor according to disability classification

> Two minds working together we figure most things out, what we can't figure out we use the specialists for. - *Comment from a survey participant*

Does this doctor handle most of your health care needs?



This question was answered by 387 survey participants and the majority checked that their doctor handles the majority of their health care needs. The 23.3% of the participants that answered *No*, stated that they have various specialists that assist them with their medical needs.

Figure 66: Does this doctor handle most of your health care needs.

MS clinic staff (neurologist, nurse, PT, OT) share my care. - *Comment from a survey participant*

Accessing medical and health services for REGULAR check ups

In regard to the question of *how often the participants access medical and health services for regular check-ups*, out of 397 respondents to this question, 30.98% of the participants that responded to this question, access regular check-ups once a year, and 27.96% access *once every 6 months*. From the five participants that responded *once a week*, one has a mobility and agility disability-related issue, one declared as no disability, and three identified multiple disabilities.

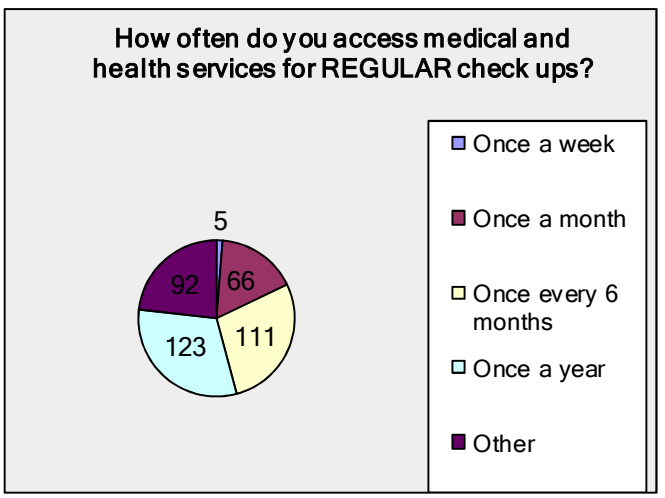
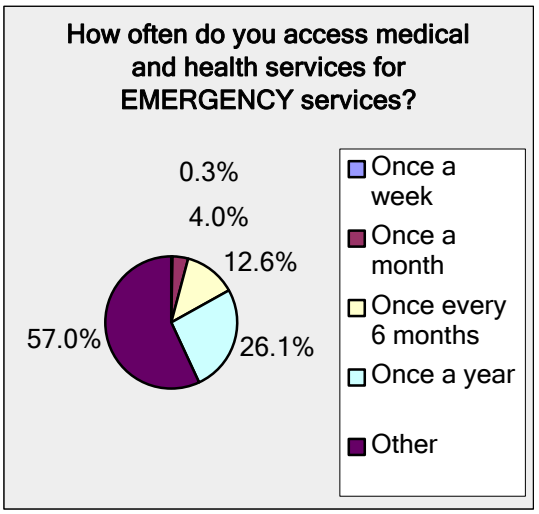


Figure 67: How often do you access medical and health services for regular check-ups?

I only access my doctor (general practitioner) in relation to my disability. He is only available when school (university) is in session. Most of my other medical needs are addressed at walk-in clinics. - *Comment from a survey participant*

Accessing medical and health services for EMERGENCY services



When accessing emergency medical and health services, the majority of the participants that answered this question (372 participants) stated that they access emergency services depending on their disability changes and needs. If they have an emergency, they tend to go or be referred to the emergency room.

Figure 68: How often do you access medical and health services for emergency services?

I only go when there's an issue. I never have 'check ups' because that would require getting on the exam table. She never assesses me. I tell her what the condition is, what I think I need, and she provides it. Sometimes I'll take a photo of the area of my body that has the issue for her to look and assess. - *Comment from a survey participant*

Diagnostic health services

The following two charts present the results from the two questions for the survey exploring the types of diagnostic services that survey participants were referred to and accessed within the past year.

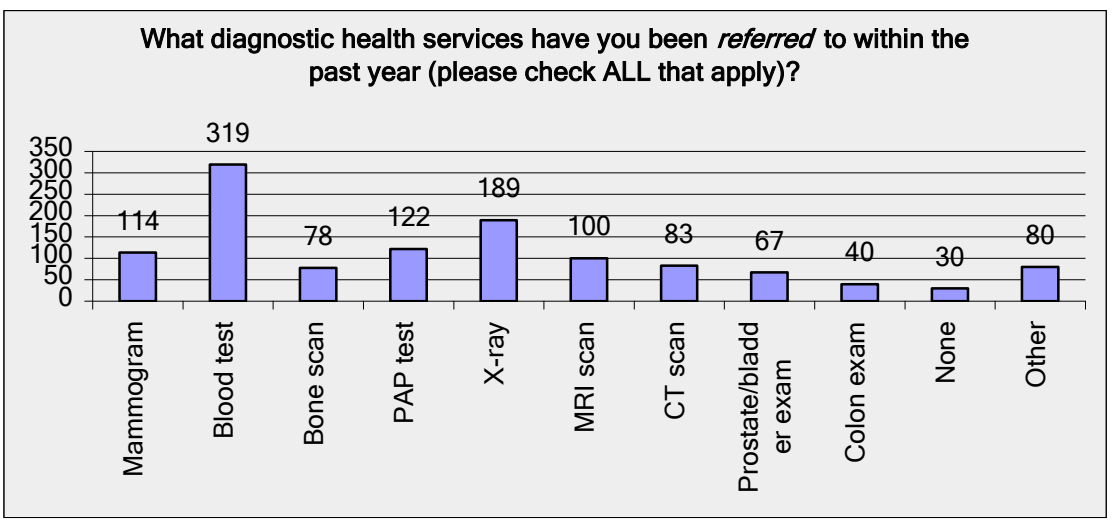


Figure 69: Diagnostic health services being referred to within the past year.

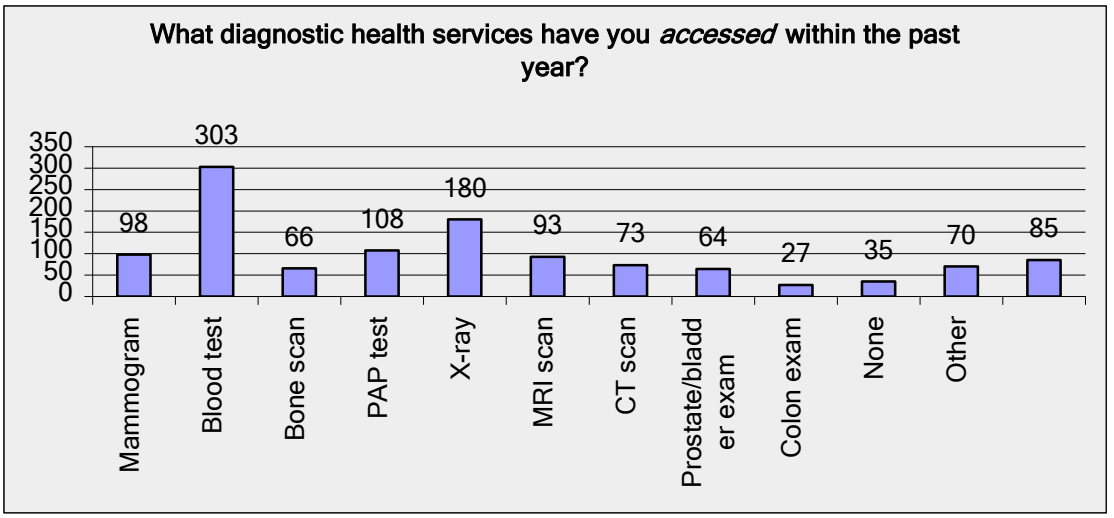


Figure 70: Diagnostic health services accessed within the past year (multiple answers)

> It's harder to access the services than it is to live with the pain. So I didn't bother trying to get the x-ray. - *Comment from a survey participant*

Accessing Health and Medical Services in Alberta

This section of the survey investigates the experienced challenges and barriers of people with disabilities when accessing health and medical services in Alberta.

Transportation

During the community consultations, one of the reoccurring challenges mentioned by participants was transportation and how to arrive at appointments on time. Participants were able to check multiple answers and the majority (77.7%) use private vehicles as a means to get to and from appointments. In addition to private vehicles, respondents (30.3%) stated that they use combination of specialized transportation and public transit, and individuals that use these types of transportation expressed that they tend to be late because of the time inconsistencies.

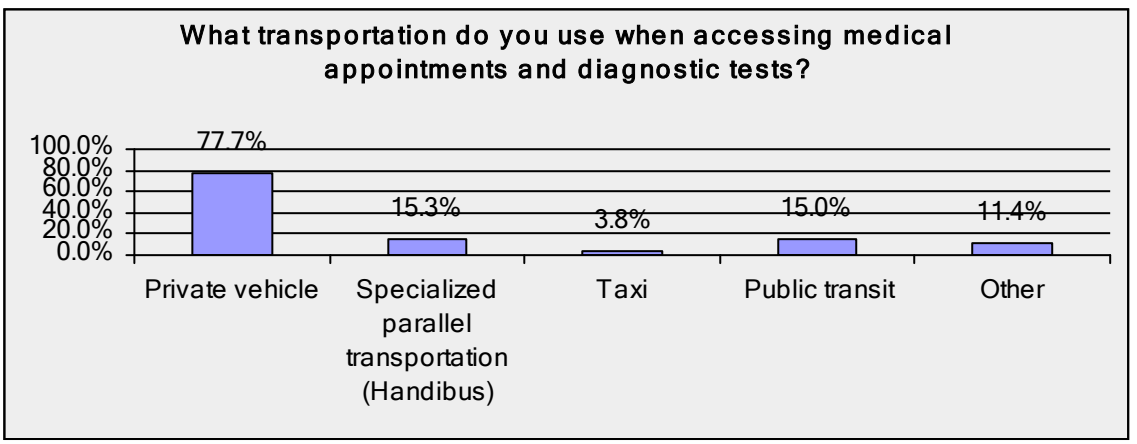


Figure 71: Types of transportation used for accessing appointments (Multiple answers)

If I could not get the correct time for my doctor's appointment from DATS, I must take the public transit system. - *Comment from a survey participant*

Participants expressed that specialized transportation like DATS and HandiBus have many limitations and do not drive to all locations. Individuals who live in areas like Stony Plain, Sherwood Park or St. Albert are not able to access these types of service because of DATS area limitations. Booking a return ride is problematic because waiting times at the doctor's office vary and the appointment might take longer than expected.

Without actual utilizing this service, I have heard from my DEAF and DEAF BLIND friends who required specialized transportation that they have utterly DIFFICULT time contacting through message relay service (TELUS) and the driver has NO means of communication (ASL) with the passengers. - *Comment from a survey participant*

Traveling to the doctor's office

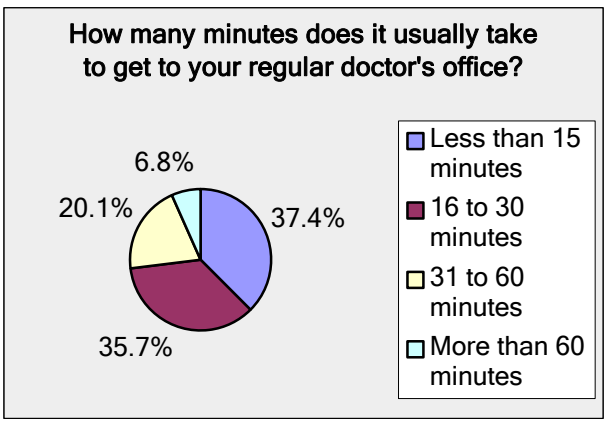


Figure 72: Travel time to medical appointments

From 486 participants, 350 answered this question and 73.10% express that it takes them less than 30 minutes to arrive at their regular doctor's office for an appointment. Survey participants living in rural areas pointed out that they are not able to access health and medical services, and they have to travel to urban locations for these necessary medical procedures services.

Depending on weather....I try to be proactive in winter and renew/refill my prescriptions early in case rural roads become risky in bad weather. My doctor works with me on this. I try to limit doctor visits by renewing all prescriptions all at same time. I had to fight Alberta blue cross to accomplish approval of all special authorization at same time as usually they don't speak directly to the client. - *Comment from a survey participant*

According to the survey results, the majority of the survey participants' offices are located near public transportation, and this allows individuals to use public transportation to and from appointments.

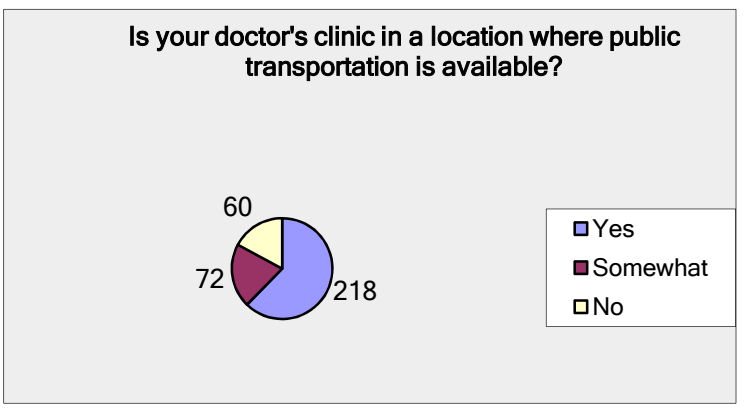


Figure 73: Doctor's clinic and public transportation availability

Physical Accessibility and Provision of Services

In this section of the survey, ACCD asked the participants to explain the accessibility of their doctor's office from outside the premises, to inside the clinic, to accessibility of the examination room, to accessibility of services that might be required by patients with various disabilities.

Outside Physical Accessibility of the Doctor's Office

The first seven questions in this section of the survey probed the physical accessibility outside of the doctor's office:

1. Are there clearly marked accessible parking stalls at your doctor's office? (***Yes*** 256, ***No*** 38, ***Not Sure*** 41, ***Not Applicable*** 21)
2. Is there a path of travel that does not require the use of stairs? (***Yes*** 316, ***No*** 24, ***Not Sure*** 6, ***Not Applicable*** 11)
3. If there are stairs, is there a ramp that allows easy access to the entrance? (***Yes*** 89, ***No*** 23, ***Not Sure*** 22, ***Not Applicable*** 166)
4. Is there clearly visible and easily understood signage to indicate entrance? (***Yes*** 271, ***No*** 47, ***Not Sure*** 23, ***Not Applicable*** 13)
5. Is there a smooth surface transition from parking to entrance? (***Yes*** 230, ***No*** 72, ***Not Sure*** 35, ***Not Applicable*** 15)
6. Are there power door operators at the interior and exterior entrances of your doctor's office? (***Yes*** 147, ***No*** 157, ***Not Sure*** 40, ***Not Applicable*** 9)
7. Is there enough space for a wheelchair/scooter to use the entrance? (***Yes*** 222, ***No*** 44, ***Not Sure*** 66, ***Not Applicable*** 19)

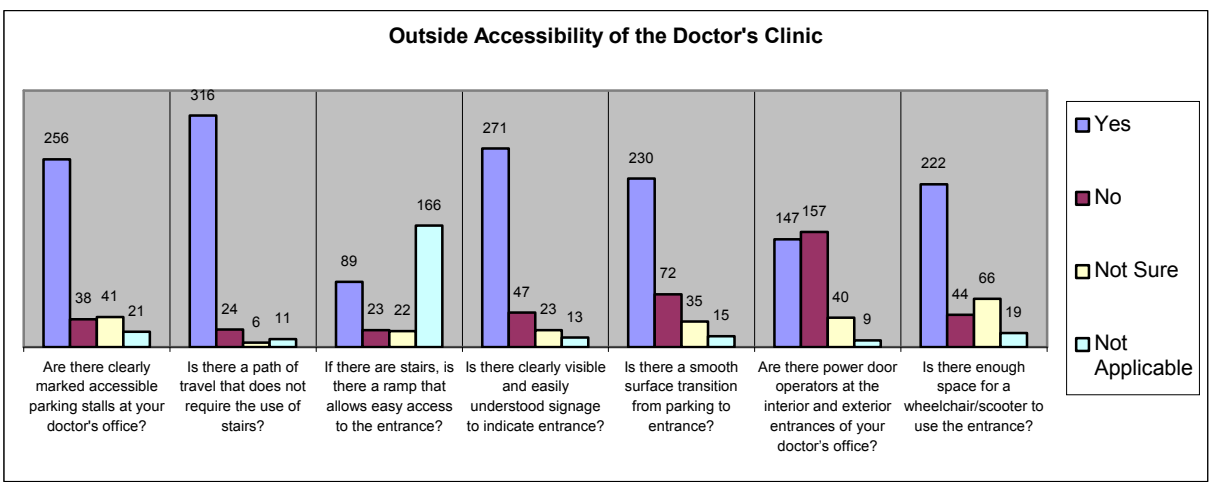


Figure 74: Physical accessibility – outside the clinic

The results show that the majority of doctor's offices that the survey participants attend are accessible in regard to parking, parking stalls, ramps, and spaces. From 353 participants, 157 stated that there are no power operated doors at their doctor's offices, and this is causing hardship for individuals who do not have the strength to open doors without assistance.

> Our medical clinic is not wheelchair assessable. It has stairs inside the building with no ramp or elevator. People with mobility issues are forced to go to the hospital to see a doctor. - *Comment from a survey participant*

Inside Physical Accessibility

The next twelve questions addressed issues with physical accessibility inside the doctor's office. ACCD designed the survey to capture accessibility issues that are currently causing challenges and barriers for people with disabilities.

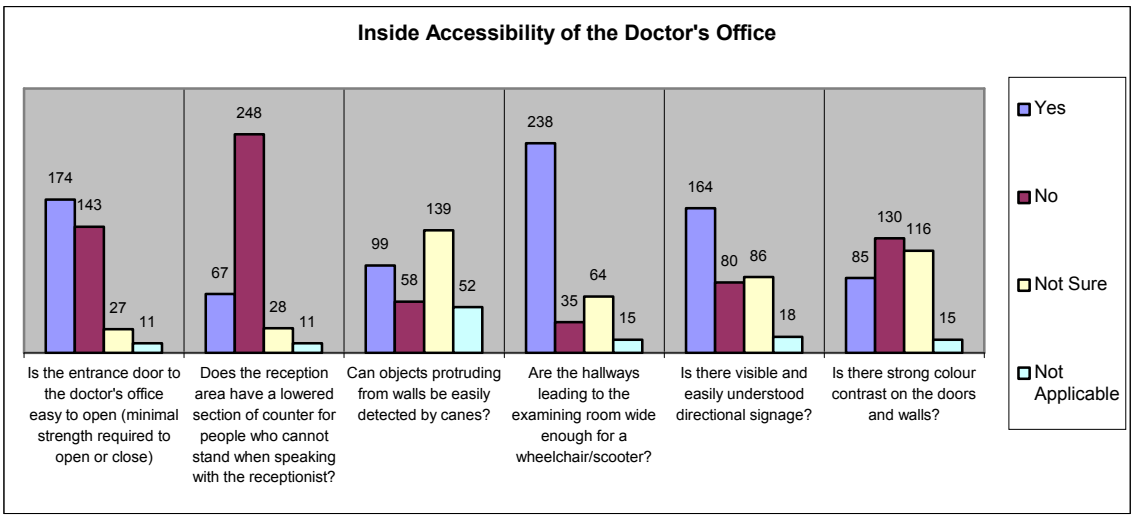


Figure 75: Physical accessibility – inside the clinic

For this set of questions, the results were fairly diverse. For 174 participants, the entrance doors are easy to open, and for 143 participants this is not the case. From the 354 participants that responded to the question *Does the reception area have a lowered section of counter for people who cannot stand when speaking with the receptionist?* 70.05% responded *No*.

In regard to the question *If objects protruding from the walls can easily be detected by canes*, 39.94% stated that they were *Not Sure*, and 37.57% stated that there is not a strong colour contrast on the doors and the walls.

Answer Options	Yes	No	Not Sure	Not Applicable	Response Count
Are there enough chairs for use by people who cannot stand while waiting?	288	46	11	7	352
Is there enough space in the waiting room for people in wheelchairs to manoeuvre/wait?	203	102	34	13	352
Is there an accessible washroom with enough space for a wheelchair/scooter to fit and close the door?	145	68	119	18	350
Is there space in the waiting room's seating area to accommodate a wheelchair or scooter?	210	89	37	15	351
Is there a scale with grabbers in your doctor's office for people who have difficulty standing?	24	136	145	38	343
Is there a washroom sign with Braille or raised-letter instructions?	18	117	161	42	338

Figure 76: Physical accessibility – inside the clinic

In regard to having enough chairs and space in the waiting room, the majority of the survey participants answered *Yes*. Many of the participants were not sure if the doctor's office is equipped with a scale with grabbers or if there is a washroom sign with Braille or raised-letter instructions.

> The washroom facilities at the Cold Lake Hospital do not have automatic doors for people stuck in a wheelchair. I have raised this issue with them - how do they expect me to reach the washroom? A money problem is always the answer. - *Comment from a survey participant*

Examination Rooms

The size and accessibility of examination rooms has been one of the major issues brought to ACCD's attention throughout the years. Many individuals with disabilities expressed concerns that the examination rooms are too small for their wheelchair and there is not enough space for their care attendant to be present during the examination process. In addition, not having height-adjustable examination tables or chairs has caused barriers for individuals who are unable to transfer from their wheelchairs to the table.

In the survey, ACCD asked survey participants about the width of the doorway leading to the examination room, the door handle of the examination room, the size of the examination room, and the availability of an adjustable examination table or chair.

The results indicate that if an issue is of no concern to a particular disability, then individuals tend to answer *Not Sure* or *Not Applicable*, because of a lack of awareness of issues that represent barriers to other disabilities. 193 individuals agreed that the doorway to the examination room is wide enough for a wheelchair/scooter; however, only 85 answered *Yes* to if the door handle is lever type. The majority of survey participants for this question were *Not Sure* about the handle.

162 participants answered *No* if there is an adjustable examination table or chair. This shows the limited access for some individuals with disabilities when trying to get on the exam table from their wheelchair or scooter. From the 353 participants that answered this question, 100 confirmed that their doctor's office is equipped with a height-adjustable table or a chair.

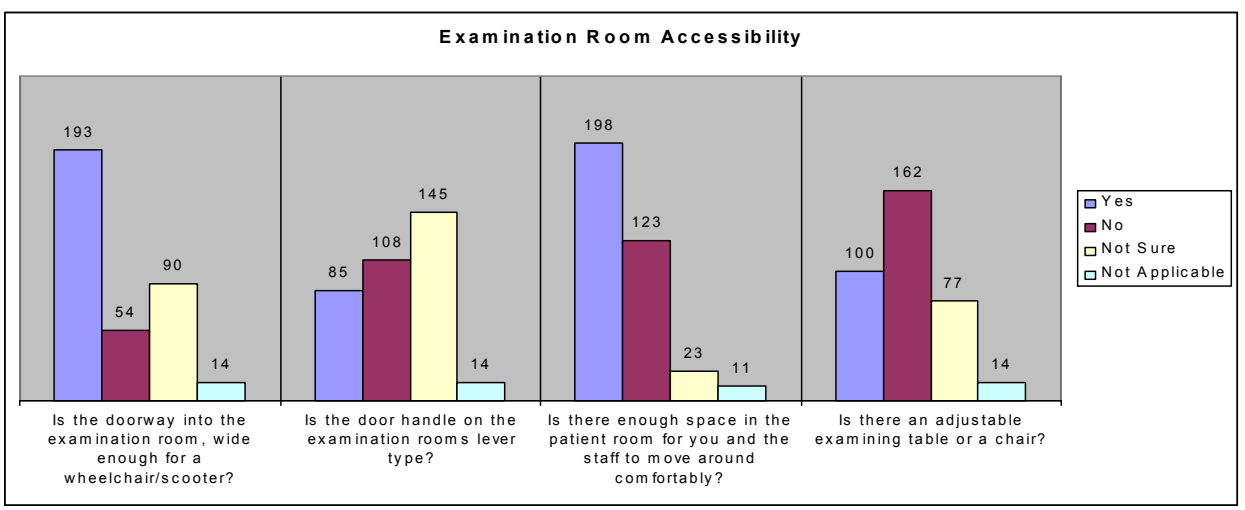


Figure 77: Examination room accessibility

Have not had an exam due to not being able to access the examination table. - *Comment from a survey participant*

Provision of Services

This set of questions was asked to find out more about provision of services that are considered necessary to eliminate barriers to health services for people with disabilities.

The first question asked participants if they had knowledge about whether the staff arranges to have a transfer team to assist individuals when moving from the mobility device/wheelchair/scooter to the table and to assist with positioning. This question was answered by 347 individuals out of which 216 (62.24%) answered *Not Sure* or *Not Applicable*. Only 41 (11.81%) participants answered *Yes*.

At home. My fiancée weighs himself, then lifts me and weighs both of us then takes the difference. - *Comment from a survey participant*

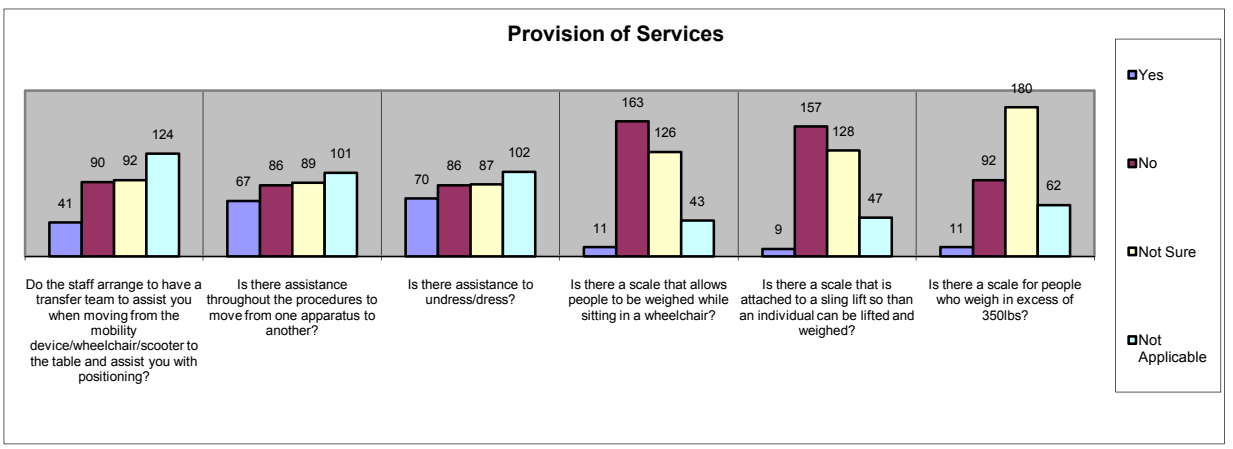


Figure 78: Provision of services

I find that when it comes to any kind of physical manoeuvring the staff are very hesitant and don't really know how to or what to do unless I tell them and I also have my own person along with me. - *Comment from a survey participant*

If there is assistance throughout the procedures to move from one apparatus to another was answered by 343 individuals and again the majority, 190 (55.39%) answered *Not Sure* or *Not Applicable* and 86 (25.07%) answered *No*. The *question if there is assistance to undress/dress* was answered by 345 participants and again only a small fraction of 70 (20.28%) answered *Yes* to the question.

ACCD has heard complaints that many individuals who are in wheelchairs or who are obese are unable to have their weight measured.

My mom bought a scale used in industry to weigh animals. My home care hangs it from my track lift, then hangs me from the scale. I don't think my doctor has ever asked about my weight. - *Comment from a survey participant*

The answers show that only small numbers of doctor's offices are equipped to deal with these situations and assist individuals to have their weight measured. Survey participants stated that if their office is located within a hospital, then they are able to provide this service to patients.

> The Steadward Centre at the U of A. A few years ago I needed to lose weight (about 40 lbs). I can't stand or transfer easily. I checked around the city and the only scale I could use was at the Glenrose. It was in fact the freight weigh scale at the loading dock in the basement! But that's not all ... the Glenrose policy was to require people to bring an assistant with them even though no transferring or lifting was required! Then a friend of mine was working as a nurse at the dialysis unit at the U of A and she showed me the role-on wheelchair scales they had. These scales were great but the hospital did not have any scales that could be used by people who were not on dialysis. The only other possibility was the Steadward Centre but their scale required transferring. Eventually I worked with the Steadward Centre and they purchased a wheelchair scale. - *Comment from a survey participant*

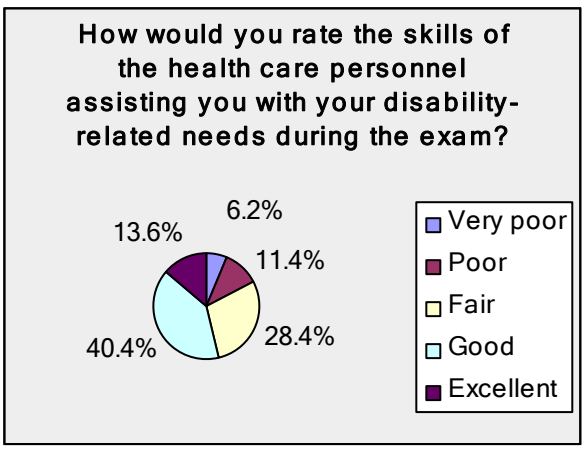
Alternative forms of communication are crucial for many Albertans with visual, hearing, speech, learning, and developmental impairments; however, only a small number of doctor's offices provide these services. The chart below shows that a very limited number of doctor's offices provide services like TTY (relay), arrangement of sign language interpreters or informational material in various formats like Braille or Plain Language.

Answer Options	Yes	No	Not Sure	Not Applicable	Skipped Question
Is there an amplified communication system or device with volume control at the reception desk?	21	118	153	50	122
Is there a TTY for use to make phone calls?	13	86	176	64	125
Are the staff knowledgeable in using TTY when contacting you?	12	40	186	97	129
If needed, do the staff arrange for sign language interpreters in advance?	9	37	187	100	131
When making an appointment are alternate formats of communication provided?	23	67	170	78	126
Is the informational material available in various formats at your doctor's office?	55	92	148	44	125

Figure 79: Availability of alternative forms of communication

The Skills of the Health Care Personnel Assisting Patients

My doctor appears to have a lack of knowledge in the area of learning disabilities and mental health. - *Comment from a survey participant*

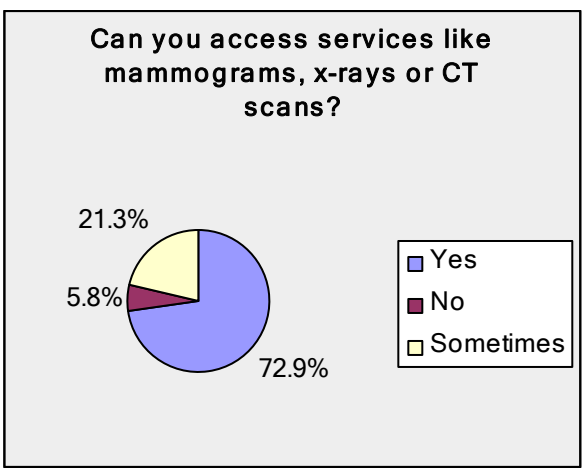


This question asked the survey participants to rate the skills of the health care personnel assisting patients during disability-related exams. 324 individuals responded to this question and 40.4% rated the skills of the staff as *Good* and 13.6% as *Excellent*. *Very Poor* or *Poor* were a choice of 17.60% of the survey contributors.

Figure 80: Skills of the health care personnel

No offer of help. Doctor comes out and calls me. Not sure if he knows I am legally blind. One of my parents is with me most of the time to assist me. - *Comment from a survey participant*

Can you access services like mammograms, x-rays or CT scans?



An overwhelming majority (250) of the participants stated that they are able to access services like mammograms, x-rays or CT scans.

The remaining 27.10% stated that the diagnostic clinics are far from their residence and there is inaccessibility medical equipment and an inability of the staff to assist them during the exams.

Figure 81: Access to services

Mammograms are tricky. The machine will adjust to the height of a person in a wheelchair but often the room itself is not big enough to manoeuvre a chair around in. X-rays and CT scans have height adjustable tables so transfers do not require lifting, but I do need help sliding across to the table. However, most facilities will NOT allow their staff to assist with transfers. Clients are told to bring someone with them. This is difficult for me as all my friends work during the day, and when I called Homecare I was told by my case manager that he was not allowed to authorize any staff to come with me, even to help me dress and undress. (Although people with memory loss and mental impairments can access homecare staff to go with them to appointments.) Bone Density (which everyone who can not stand or walk should have) are the most difficult. This is because the machines do not lower and one must be lifted on to the table. The place I go to is buying a portable Hoyer lift.- *Comment from a survey participant*

Where do you access services like mammograms, x-rays or CT scans (multiple answers)?

Survey participants access services like mammograms, x-rays or CT scans mainly in diagnostic clinics (68.5%) and/or hospital settings (51.8%).

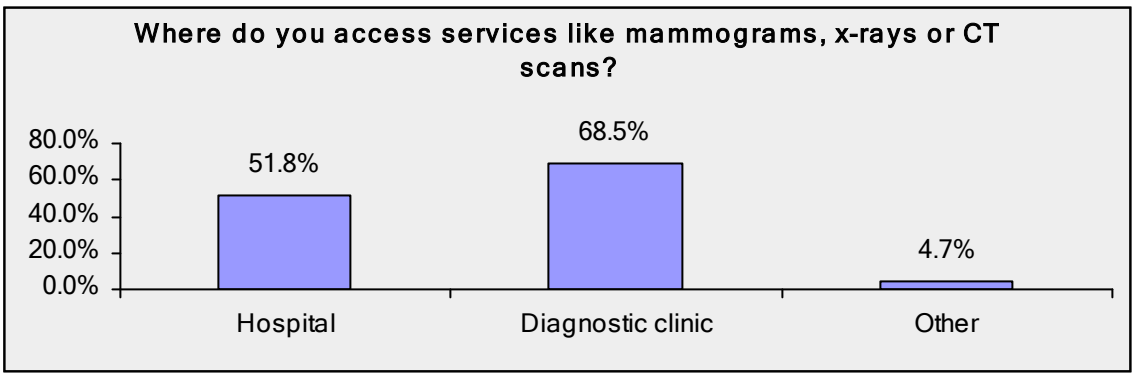


Figure 82: Where do you access services?

The participants that answered *Other*, stated that on several occasions the doctor came to perform the test at their home, or they have not had a mammogram for more than three years. A few individuals answered that they accessed these services at private clinics.

> I have used both and some places have some adaptable equipment but most do not. - *Comment from a survey participant*

Personal Experiences

The following statements are from the survey participants about barriers to health and medical services[312]:

- If my family isn't available to help transfer me, I generally don't have the test. Often the staff who are trying to do the transfers don't have enough experience and I don't feel safe with them. It's one thing to get me onto the table for the test. The next thing is to be sure I don't fall off. And finally I have to get back into my chair properly so I'm comfortable for the rest of the day.
- I sometimes don't know what the words mean. or what I am supposed to do.
- An MRI was booked at a time when there was not adequate staff to assist with lift so had to be rescheduled.
- Went to Hys Center for bone densitromity test could not get on examining bed did not lower no help to get on table had to reschedule to different location and made sure I had lots of help come with me to lift on bed same at university hospital to get MRI.
- The eye exam was difficult. It was hard to reach my eye to the place where the machine took pictures of it. We were able to do it after moving the equipment getting someone to help me hold my head in the right place.

[312] These statements are taken directly for the survey and are verbatim.

- X-ray, Bone scan & even some MRI (Misericordia Hospital) Labs NEVER have lifting equipment. They require my caregivers to manually lift & transfer me.
- PAP tests. Cannot get up on the doc's table, so had to make special arrangements to go to the pelvic floor clinic.
- For those of us with mobility problems, the distances involved in most hospitals make it exhausting to get from A to B in the time that is often necessary, makes it stressful. Sometimes staff have failed to inform one of a change of venue for an examination so you have been waiting in the 'wrong' place & sometimes miss your appointed time & then you get 'scolded' for not being on time! If you mention to them that you had not been properly informed, they can act quite impolite, as it is always the fault of the patient. No wonder I have developed distaste for seeking examinations unless it becomes an urgent matter.
- When the technicians are wearing cologne, scented body or hair products, or laundry fragrance on their clothing, it makes me ill. I get an asthma attack and migraine.
- My doctor has tried to refer me for a colonoscopy but he is having trouble finding a doctor that will perform the procedure on a paraplegic.
- Yes because I am a larger gal, I have had issues with the facilities not being able to accommodate a person that is larger and the equipment is not designed for people of all sizes. If I am not able to be accommodated in a regular diagnostic center, then I have to make arrangements and go to a hospital.
- The delaying when you need to book an exam. Depending on the exam, your waiting can last for 6 to 10 months. This is not fair when you need a prompt diagnosis.

The Service

Knowledge, Coordination and Manner

Participants were asked to rate following:

- The knowledge of the additional medical personnel (specialists, technicians, reception, nurses, and other doctors) of you as a patient?
- The coordination between the additional medical personnel (specialists, technicians, reception, nurses, and other doctors) and your regular doctor?
- The personal manner (courtesy, carefulness etc) of the health care professional at your doctor's office?

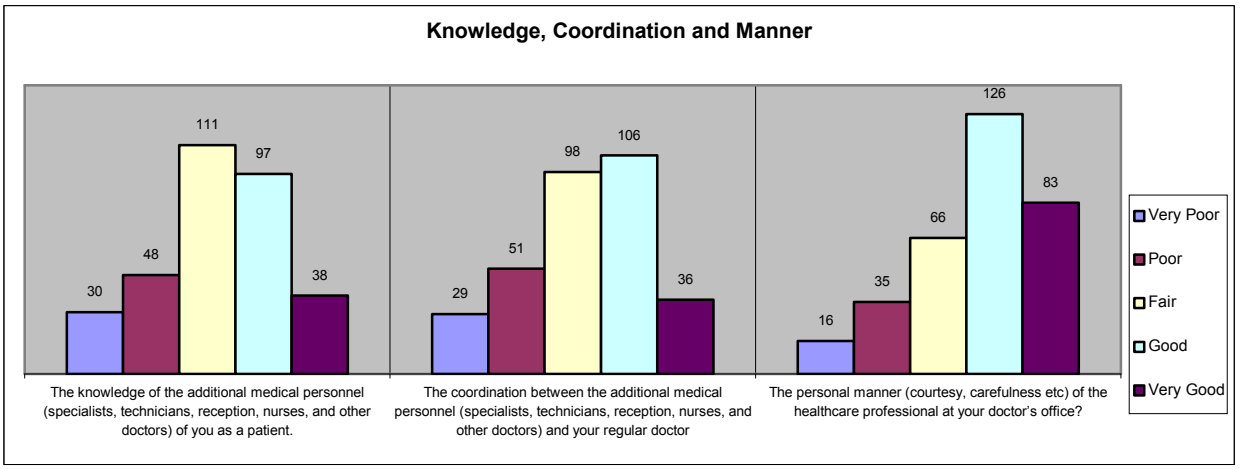
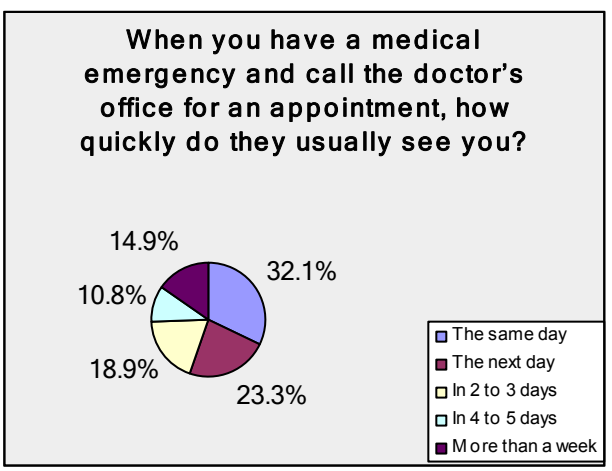


Figure 83: Knowledge, coordination and manner of staff

As the chart above shows, participants expressed concerns about the knowledge, coordination, and courtesy of medical personnel. The knowledge of the additional medical personnel was rated by 111 participants and the coordination or services by 98 individuals as *Fair*.

Making Appointments

> Average wait time for a specialist is a year. The only time this wasn't true was a TMJ specialist that AISH didn't cover and so I had to pay $325 out of pocket for a 15 minute visit only to be told that he couldn't do anything because he is an orthodontist and can't move up 2 centimetres to broken sinuses. It would have been nice to know this prior to being billed at the TMJ clinic, obviously he would have known from seeing me there. That was highway robbery. - *Comment from a survey participant*



When individuals attempted to book an appointment in emergency situations, 95 (32.1%) answered that they have been able to see the doctor the same day. Forty-four stated that it takes more than a week to see the doctor in an emergency situation. A common theme emerged from the participants that when they call their doctor's office with an emergency, the staff refer them to the emergency room.

Figure 84: Appointments during emergencies

> With my Doctor, I would be lucky to be able to get an appointment in SIX weeks. His services are very difficult to access & if I complain, I am told to go find another Doctor. Needless to say, another Doctor is most difficult to obtain. - *Comment from a survey participant*

In non-emergency situations, 105 (32.5%) stated that they are able to book an appointment within a week. Thirty-five said it takes more than a month to see their doctor.

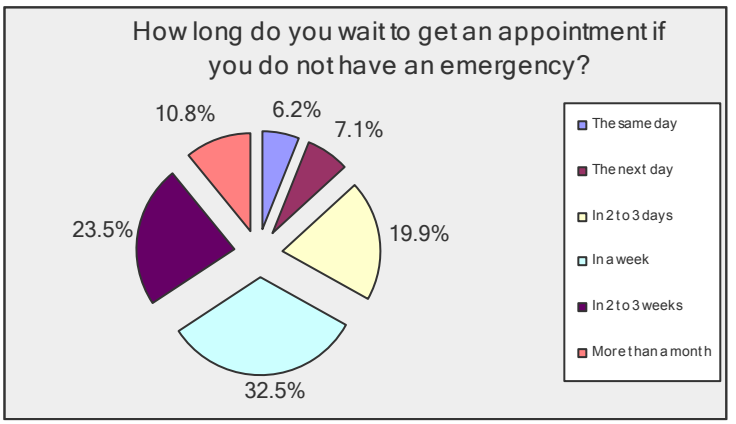
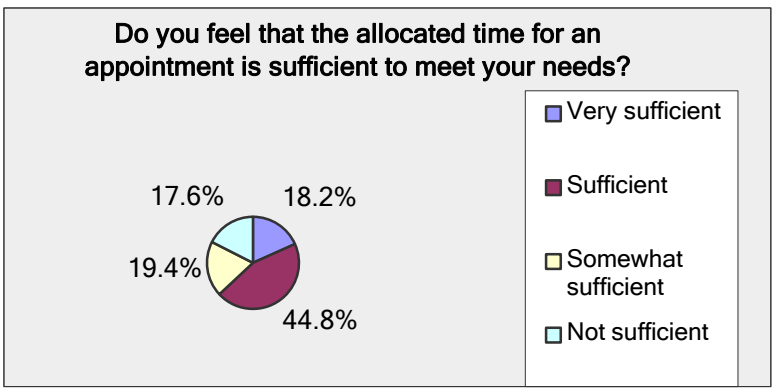


Figure 85: Appointments without emergencies

> Over a month notice is required to see my psychiatrist. - *Comment from a survey participant*



When asked about sufficient time for an appointment, 145 participants marked *Sufficient*, and 59 marked *Very Sufficient*. Fifty-seven of the 324 participants marked Not Sufficient.

Figure 86: Appointment times

> Too rushed to be adequate, treated like cattle, not patients.....no one doctor learns enough about you as a patient to make an informed decision regarding your (my) Medical needs.- *Comment from a survey participant*

Accommodate disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)

From all survey participants, 58.9% answered this question agreed that their doctor accommodates most of their needs. A few participants who are Deaf stated that because the doctor is not able to provide Sign Language interpreters, they have to communicate by writing, even though this is not a preferred method of communication.

Does the doctor's office accommodate your disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?		
Answer Options	Response Percent	Response Count
Yes	58.9%	165
No	23.2%	65
Sometimes	17.9%	50
	answered question	280
	skipped question	184

Figure 87: Accommodation of disability needs

I am VERY fortunate and it took me a long time to find this doctor. He is the exception and part of a dying breed, I'm afraid. However because of the generation he grew up in I feel he tends to focus on my disability and not my ability. When we first met he was very surprised to hear that I worked full time, almost to the point of denial. - *Comment from a survey participant*

Personal Perspectives

The following section of questions explores the personal experiences of people with disabilities when accessing health and medical services in Alberta.

My doctor sees my abilities rather than my disability

In the ACCD survey, we asked participants to state if their doctor sees their abilities rather than their disabilities. 211 of the participants that answered this question agreed that their doctor sees their ability rather than disability.

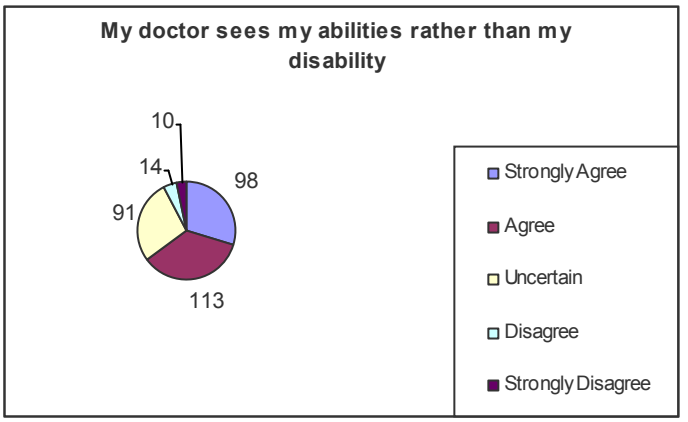
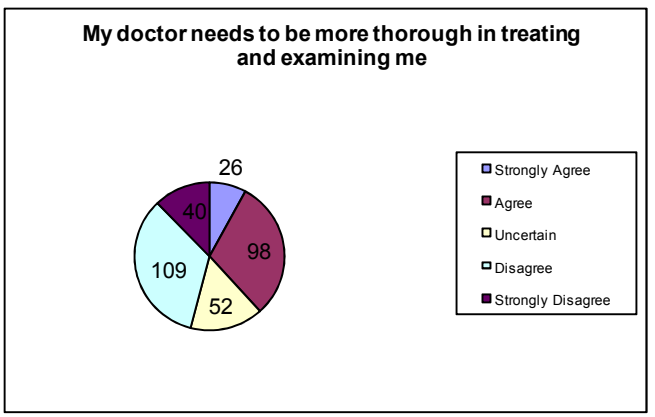


Figure 88: My doctor sees my abilities rather than my disability

At times I don't know what to ask. He speaks to my parents, not to me. Asks my parents if I need anything else instead of asking me. - *Comment from a survey participant*

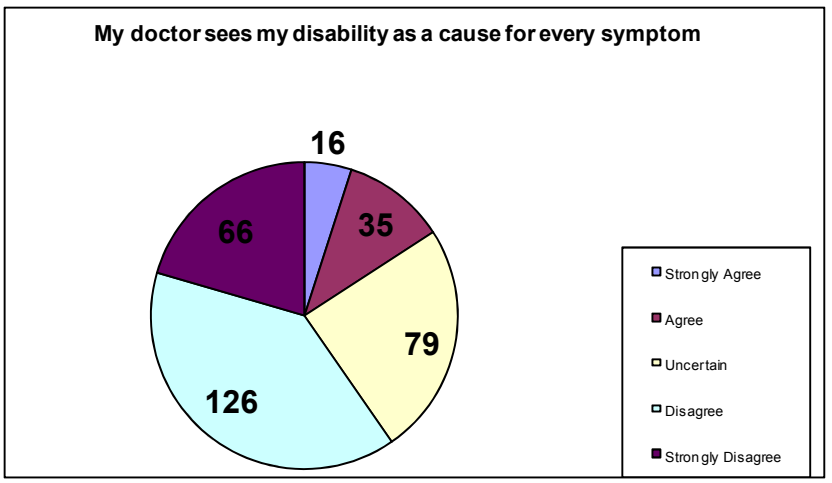
My doctor needs to be more thorough in treating and examining me



149 survey participants that responded to this question, answered *Strongly Disagree* or *Disagree* that their doctor needs to be more thorough in treating or examining them. 124 participants stated that the doctor needs to be more thorough.

Figure 89: My doctor needs to be more through in treating and examining me

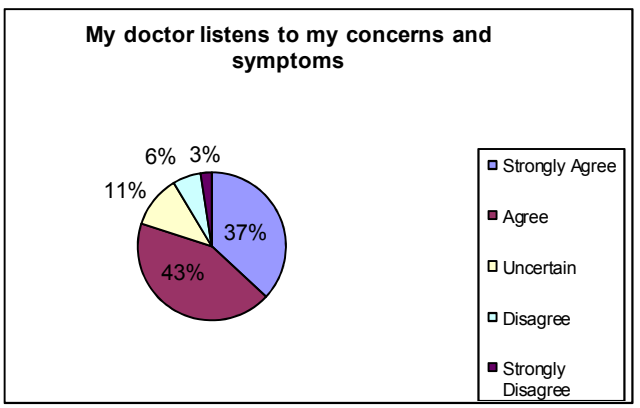
My doctor sees my disability as a cause for every symptom



Only 15.84% of the participants *Agree* or *Strongly Agree* with this statement. 24.54% were uncertain and 59.62% *Disagree* or *Strongly Disagree*.

Figure 90: My doctor sees my disability as a cause for every symptom

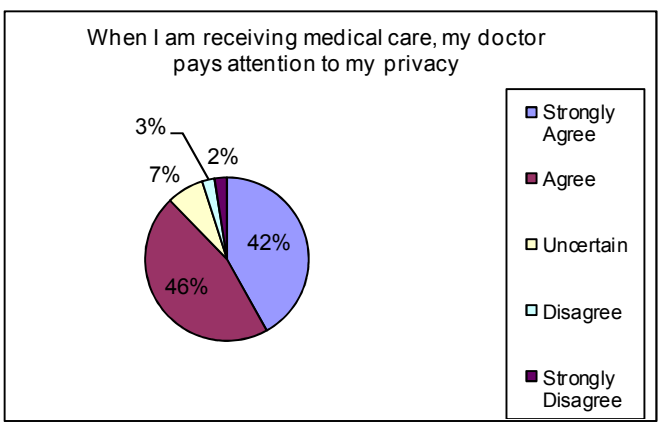
My doctor listens to my concerns and symptoms



81% of the 325 survey participants that responded to this question marked *Agree* or *Strongly Agree*. In the comments area, participants expressed frustration about general practitioners understanding various disabilities; however, these individuals acknowledge that it is impossible for one medical professional to understand and respond to the diversity of disabilities.

Figure 91: My doctor listens to my concerns and symptoms

When I am receiving medical care, my doctor pays attention to my privacy



287 survey participants from 327 marked *Strongly Agree* or *Agree* that their doctor pays attention to their privacy during medical care. The 4% that disagreed with this statement, pointed out that medical personnel speak loudly in the reception area about treatment and diagnosis when the patient comes for an appointment.

Figure 92: My doctor pays attention to my privacy

> Not a lot of privacy in front end of either doctors offices or entering emergency - you won't give out medical info but you sure have everyone broadcast it when we show up for appointments or help. - *Comment from a survey participant*

It is easy for me to get medical care

From 324 participants that responded to this question, 81 marked *Strongly Disagree* or *Disagree* with the statement that it is easy for them to receive medical care. 195 survey participants express that it is easy for them to get appropriate and necessary medical care in Alberta.

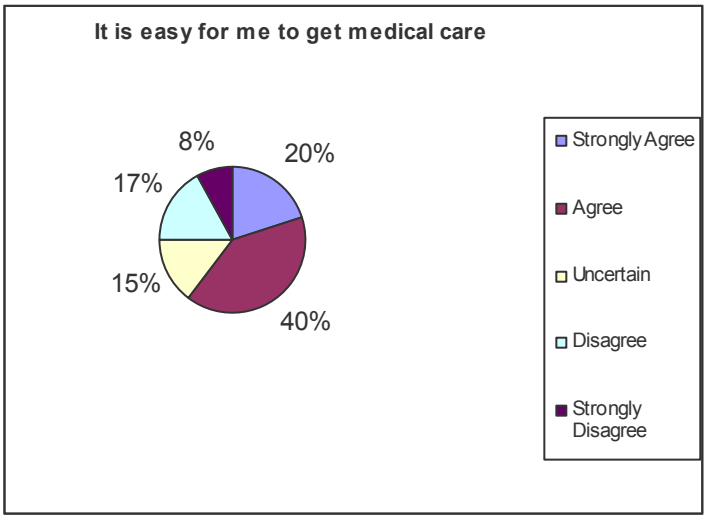
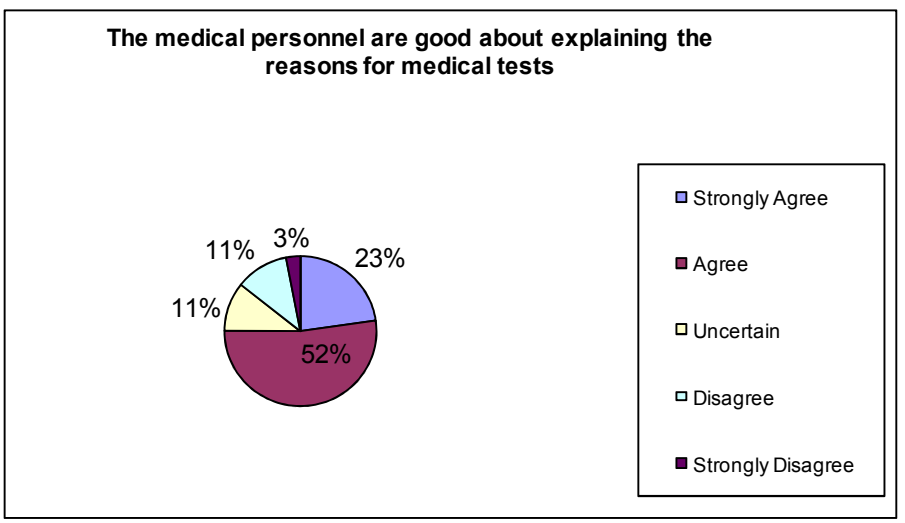


Figure 93: It is easy for me to get medical care

> Medical Services in the Encana Wellness center are limited; doctors are 45-80 minutes behind schedule, the doctor is always rushed and isn't able to listen to my concerns, so many underlying issues go unresolved. With that being said, I don't believe the fault is with the doctor; she does her best to be a thorough as possible but there just isn't enough time as appointments are allotted only 10 minutes.- *Comment from a survey participant*

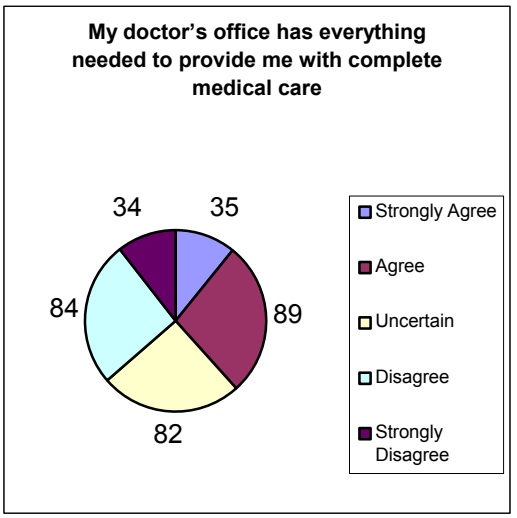
The medical personnel are good about explaining the reasons for medical tests



The majority of survey participants expressed positive statements about medical personnel explaining the reasons for medical tests. Only 47 individuals from 325 disagreed with this statement.

Figure 94: The medical personnel are good about explaining the reasons for medical tests

My doctor's office has everything needed to provide me with complete medical care

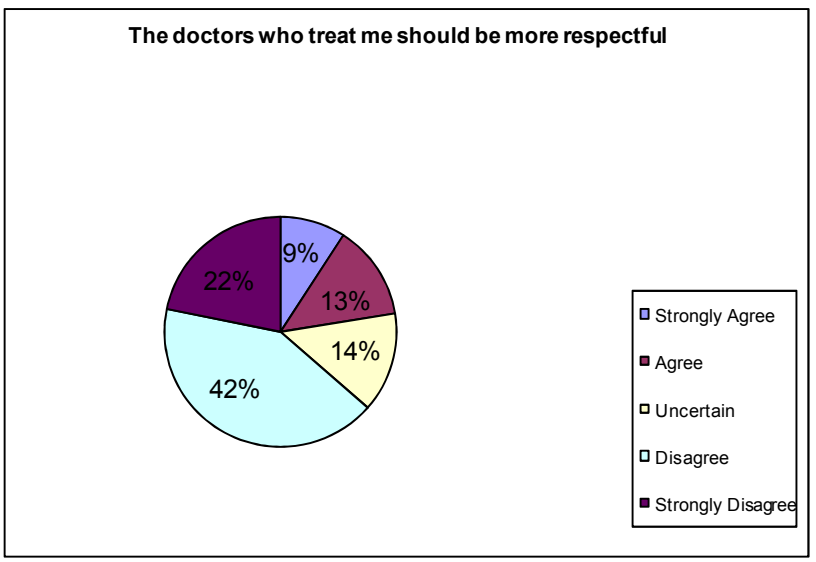


In regard to this question, 25.31% of participants were *Uncertain* about whether their doctor's office has everything to provide complete medical care. *Strongly Agree* or *Agree* was a choice of 38.27% of individuals in the survey. Almost equally, 36.42% of participants marked *Disagree* or *Strongly Disagree*.

Figure 95: My doctor's office has everything needed to provide me with complete medical care

When comes to MS/epilepsy, specialist often want you to see GP. GP doesn't know a lot of things necessary to comply, including medications, general. - *Comment from a survey participant*

The doctors who treat me should be more respectful

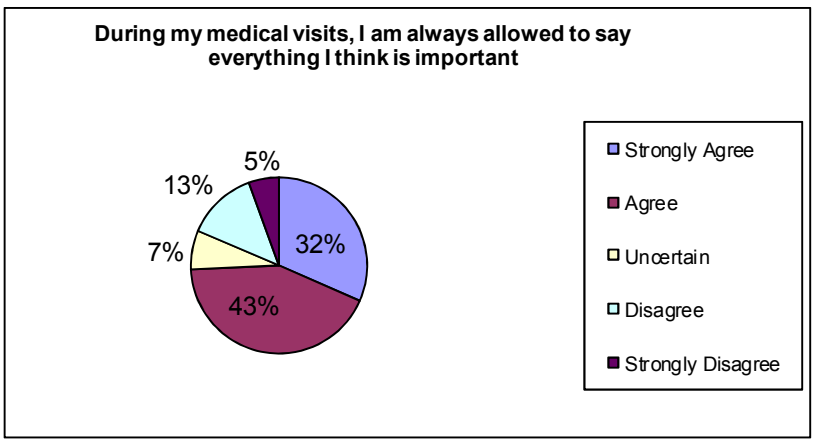


From 316 answers, 63.60% of the participants that answered this question *Disagreed* or *Strongly Disagreed* with this statement. 22.46% of the participants *Agreed* or *Strongly Agreed* that their doctor should treat them with more respect.

Figure 96: The doctors who treat me should be more respectful

My doctor tells me that my issues are all in my head. - *Comment from a survey participant*

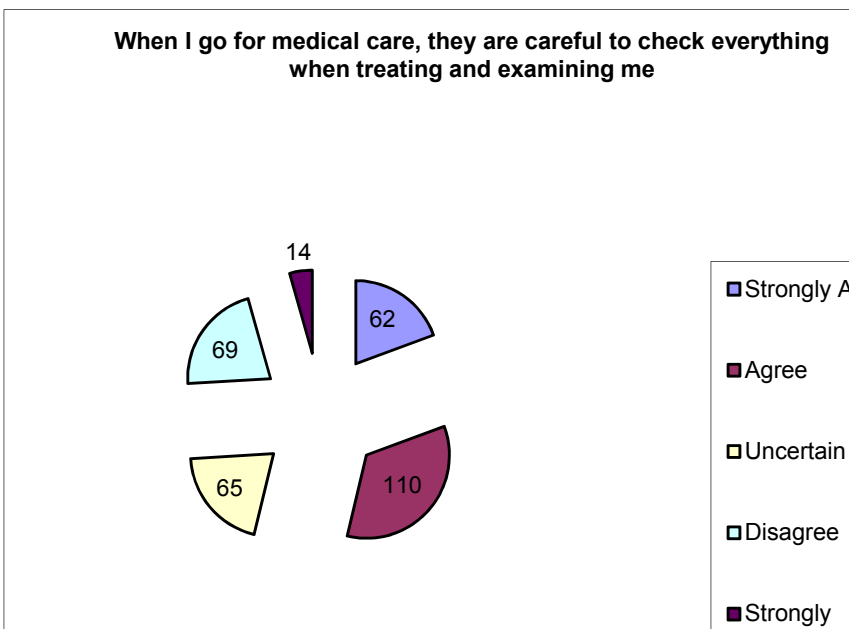
During my medical visits, I am always allowed to say everything I think is important



For this question, 75% from 323 participants answered *Agree* or *Strongly Agree*, and 18% marked *Disagree* or *Strongly Disagree*.

Figure 97: During my medical visits, I am always allowed to say everything I this is important

When I go for medical care, they are careful to check everything when treating and examining me



53.75% of the 320 participants responded to this question with a positive attitude, and 25.93% expressed concerns that their disability symptoms are not easily diagnosed and at the end, the patient and the medical professional experience frustration and a state of disappointment.

Figure 98: Doctors are careful to check everything when treating and examining me

My doctor doesn't seem to know what to do with me. My symptoms don't seem to have a treatment but I often feel that because of this, I'm referred for tests that don't directly contribute to solving my main concerns. I'm not keen to go for a lot of tests and don't have the energy to lots of times so I don't always follow up on what is recommended. An analogy for this: I go to the doctor with a broken wrist and rather than send me for x-rays or splint the wrist, I'm sent for a scan of my leg. Just misses the boat. - *Comment from a survey participant*

It is hard for me to get medical care on short notice

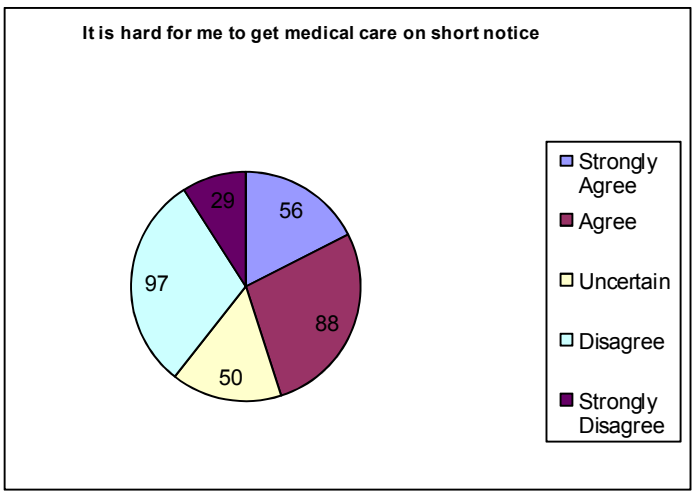


Figure 99: It is hard for me to get medical care on short notice

45% of 320 *Agreed* or *Strongly Agreed* with this statement and 39.37% marked *Disagree* or *Strongly Disagree*. From the 320 that answered this question, 15.63% were Uncertain about getting medical care on short notice. Participants expressed that most of the time when they experience a medical emergency, the first recommendation is to go to the emergency room and try to get access to medical and health services at that setting.

The doctors who treat me have a genuine interest in me as a person

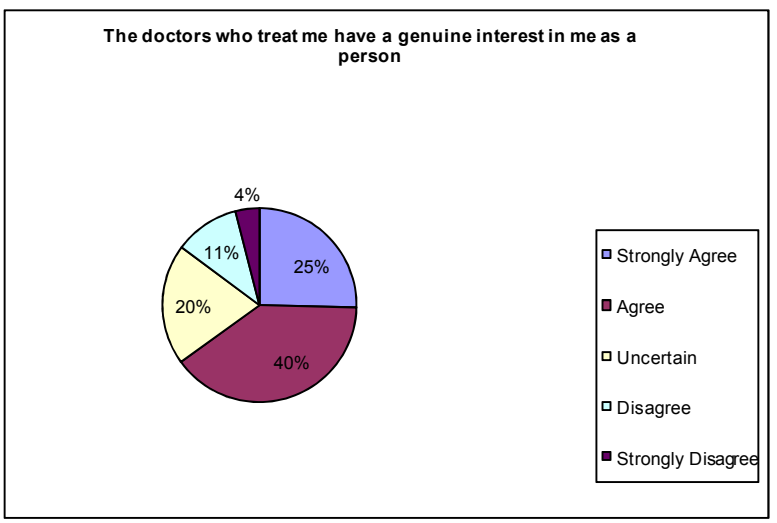
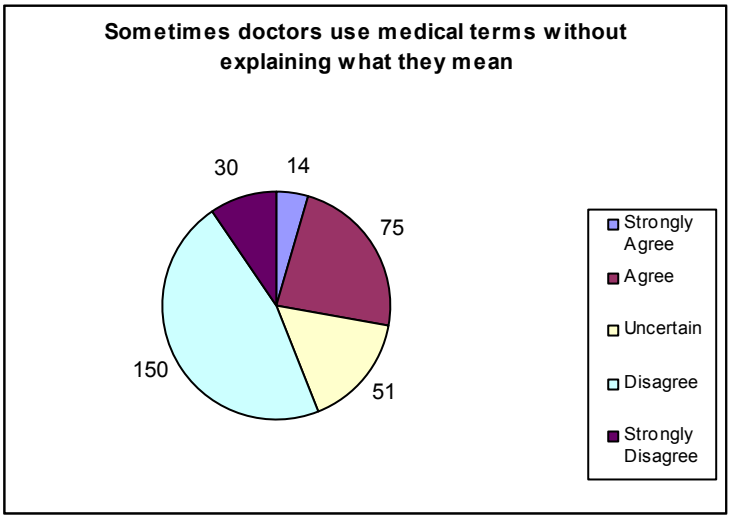


Figure 100: The doctors who treat me have a genuine interest in me as a person

Majority (210) of the 323 participants that responded to this question *Agreed* or *Strongly Agreed* with this statement. *Uncertain* was a choice of 65 individuals and 48 individuals checked *Disagree* or *Strongly Disagree*.

My GP is very good. He listens well, treats me with respect, is open to discussing new treatment options, and is supportive. Many specialists are not. Some are arrogant. Some are at least a decade behind in their research. I know this because I've asked them about treatments that have been available for ten years or more, and I have yet to meet specialists who know much, if anything, about them. I don't expect the specialists to agree with every treatment, but I expect them to know about them--especially when the treatments have been reported in well-established journals and researched at large research facilities in the USA and elsewhere. Because they are behind in their research, I have to fight these specialists for the treatment I am on now (developed by American MDs). When local specialists tinker with my treatment (as they often do), I'm the one who ends up bedridden for 3 - 6 months, but I often can't get them to listen.- *Comment from a survey participant*

Sometimes doctors use medical terms without explaining what they mean

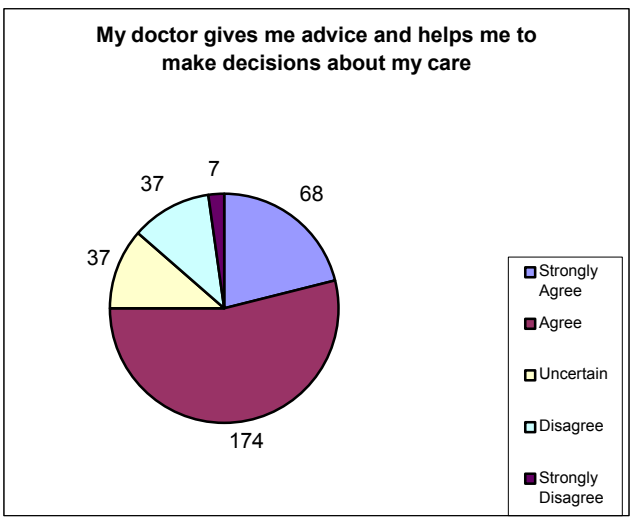


27.81% confirmed *Agree* or *Strongly Agree* with the statement that sometimes doctors use medical terms without explaining what they mean. One hundred and eighty participants from 320 pointed out that they get very good assistance from medical professionals about their diagnosis and treatment.

Figure 101: Sometimes doctors use medical terms without explaining what they mean

> Especially in the hospital, the hospital doctor did not treat me with respect (my GP does), the hospital doctors used medical terms without explaining what they meant. - *Comment from a survey*

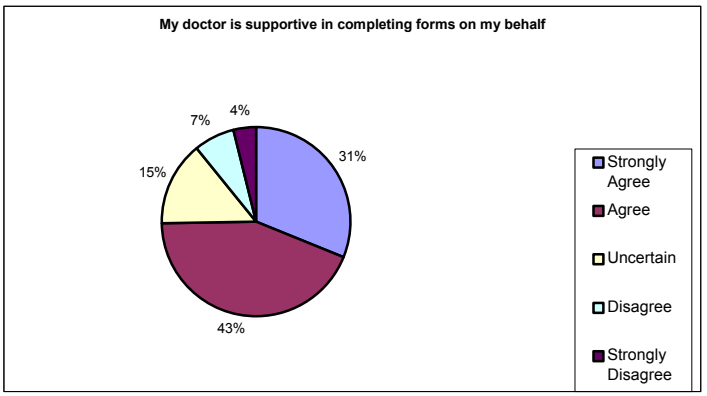
My doctor gives me advice and helps me to make decisions about my care



74.92% of 323 pointed out that their doctor gives them advice and helps them to make decisions about their care. Thirty-seven were *Uncertain* and 13.62% expressed negative perceptions and stated that it all depends on their symptoms and the doctor's willingness to explore other methods of care.

Figure 102: My doctor gives me advice and helps me to make decision about my care

My doctor is supportive in completing forms on my behalf



For people with disabilities, medical forms that are filled out properly and efficiently means getting on various social-assistance based programs or being denied services. In our community consultations, ACCD heard numerous complaints about doctors not having enough time to fill out forms for individuals.

Figure 103: My doctor is supportive in completing forms on my behalf

In the survey, ACCD found out that 74.69% of the participants stated Agree or Strongly Agree that their doctor is supportive in completing forms on their behalf. Only 10.80% expressed frustration with having forms completed on time and with all the necessary information. Forty-seven individuals were *Uncertain* if their doctor is supportive.

> Any time my Dr. signs a form for me, I am whacked with a Bill... minimum $35.00. - *Comment from a survey participant*

How often do you leave your doctor's office with unanswered questions?

Three hundred and twenty-six individuals responded to this question and 39.9% stated that *Almost Never* they leave their doctor's office with unanswered questions. 32.2% marked that *Some of the Time* they leave with some unanswered questions. Fifty-two participants checked *Always*, *Almost Always* or *A Lot of the Time*. Many participants commented that they write their questions at home and come prepared because of the short time allocated for appointments. Others wrote that their doctor refers them to specialists if there are questions that they are not able to answer for the patient.

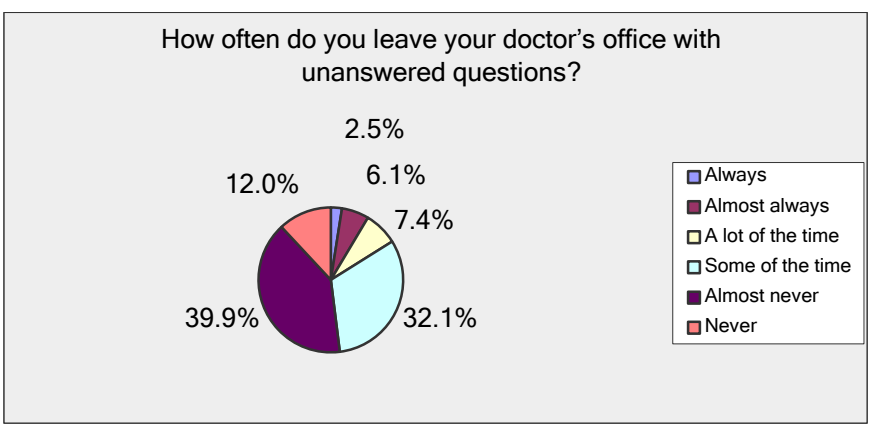
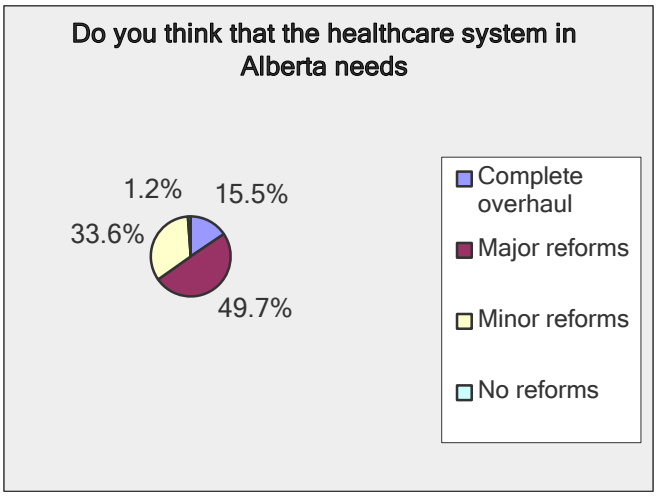


Figure 104: How often do you leave your doctor's office with unanswered questions?

> If my doctor cannot provide me with answers, he will refer me somewhere that I can get the answers I need. - *Comment from a survey participant*

Do you think that the health care system in Alberta needs

> I think that more preventive and especially immediate care of illness or injury would prevent many conditions from becoming more serious and costly. Waiting times are too long in emergency and for tests and specialists. I think there should be regular mandatory reviews of medications for those with complex health needs. - *Comment from a survey participant*



The majority of the ACCD survey respondents believe that the health care system in Alberta needs *Major Reforms*. 33.5% believe that it needs only *Minor Reforms* while 15.5% marked that the system needs *Complete Overhaul*. Participants pointed out that if the government invests in preventative care, then the cost for health care might decline significantly and people will access the health care system less and less.

Figure 105: Changes to the Alberta health care system

> I hesitate to say anything but "minor reforms" because people seem to use that as a justification for advocating private health care - definitely NOT what I want to see. I do think the best thing our health care system could do is have GPs and specialists work in groups so patient's information can be shared and faster diagnosis/treatment decided upon. Trying to obtain a diagnosis for my problem (ultimately determined to be MS) took almost 4 years of many referrals and no one talking to the other specialists. Needless - and difficult - waiting is involved. Also, it seems our GPs are now just "referrers" - they don't seem to actually touch patients and don't want to. For example, need a needle - see a nurse! Have an infected wound that needs to be opened to drain - take antibiotics instead of having it opened. Too dangerous! Well, so are antibiotics. - *Comment from a survey participant*

What would you like to see improve immediately in your access to medical clinics and diagnostic tests?

This was an opened ended question and the following are some of the suggestions from the survey participants:

- Be paid for physiotherapy. Physiotherapy at $90.00 per visit keeps seniors away from getting help, even me.
- Better signage on doors and elevators (for the blind).
- Access to testing and treatment for CCSVI to open up blocked veins using angioplasty. This is available for other patients who do not have MS and should be available for those of us who do.
- Transportation needs to be easier to access. The door to my doctor's office is very hard to open.

- That all my information would be somewhere in one place where different doctors could see it so I won't have to explain all about myself every time.
- I would like to see a doctor in few days of appointment rather than waiting few weeks and then forgetting about the problem. Able to discuss everything in one sitting.
- More accessible washrooms.
- Shorter wait times.
- MRI, x-ray blood back in the doctor's offices or at least adjoining.
- Height adjustable examining tables, portable Hoyer lifts, roll-on wheelchair scales at government community health care centres (name?) and homecare support for personal care attendants to go to medical appointments.
- Educating hospital staff on physical and mental disabilities; enough to provide working knowledge. Also the emotional trauma children with disabilities face; showing empathy.
- Accessibility in regards to examination tables e.g.: ceiling lifts, weight scales and informed and trained staff to use them correctly or ask the clients for input.
- One location in each major centre to handle women's issues would be the most cost effective. It would have access, equipment and trained staff on site. It isn't reasonable to have such facilities at a regular doctor's office. Some location such as the Lois Hole Hospital in Edmonton could have a special clinic specifically set up for women like me. Those needing the specialized services should get priority for appointments, but others could use it as well to keep it cost efficient. Specialists could then be available at that clinic to assess the woman's health in all areas (i.e. gynaecologist).
- When Specialist says need blood test or other test, either directly give request for test or ensure GP knows test is needed, no questions asked.
- All clinics should be easily accessible. I could not use many of them without my husband's assistance. Luckily my husband is strong to lift my wheelchair to move me in certain directions where hallways are skinny and difficult to turn corners. On some corners there are marks on the walls and corners from wheelchairs or scooters.
- Ability to access medical services more quickly and effectively when required. Increase handibus access by increasing the number of buses and operation dates for this service. Too many people are left with being unable to get to their appointments and that is not acceptable. You should be able to get to your medical appointments as required.
- Each medical clinic across Alberta should have a barrier free standard in office layout and equipment thereby eliminating the question, Will I be able to access the office and will I be able to have a thorough examination, if needed. This would be helpful not only for wheelchair bound but useful for crutches, walkers, and adjustable tables for shorter individuals, elderly even pregnant ladies.

- Improve EMS services! Improve emergency room triage.
- For all medical services to comply with both human rights and building codes as related to providing services to persons with disabilities (e.g. every office should have an adjustable height examination table, all staff should have disability awareness training)!
- Full access to ASL interpreters.
- More understanding of mental illness and addiction.
- Treat nurses and other health care professionals with respect. Stop making them work split shifts and part-time. Overhaul the hierarchy in the hospitals. There are too many middle managers with no health care experience. Provide workers with protection against workplace bullies (there are many in the health care system--especially the hospitals--and no one is dealing with them. We are losing skills nurses and technicians because of poor working environments. Stop following the drug model of care, and start incorporating money-saving treatments such as nutrition, massage, chiropractic, and other "alternative" therapies that are more effective and cheaper than drugs and surgery.
- All hospitals, clinics, doctors offices, diagnostic and other labs need to have a scent free policy. They are supposed to help people get well or obtain testing, not make a person ill. Cologne, scented body and hair products, laundry scent on clothing, all have chemical fragrance in them. Patients with asthma, allergies, COPD, chemical sensitivities, and respiratory illnesses are made ill by having to be exposed to these. We can choose not to go to a public gathering or concert or meeting, but we cannot choose not to go to the hospital, doctor's office, lab, other medical facility when we need to be treated for something.
- More doctors who understand and communicate in clearly understood English and can access a family doctor that is not a walk in clinic. Medi Centres are being used instead of a family doctor because there are no family doctors around in my area of the city that are accepting new patients and can clearly communicate in English and are easily understood.
- I am impressed with the care that I personally get. I believe it is a two-way street, I respect my physician and he/she respects me. I don't waste their time and I don't expect them to waste mine.
- More respect from staff at diagnostic centres as they can be quite rude.
- A lowered counter so that the receptionist can see me and I can see her. Also examination tables that can be lowered so that I can transfer from my chair to the table more easily.
- Ability for all exam tables or tables used for services to be able to be lowered/raised or an alternate means of getting patients onto the table/machines. When booking an appointment the person’s disability should be highlighted so the person doing the booking can ask or be told any limitations that may be faced by the clients.

- Access to accessible medical exams / procedures (accessible exam tables). Disability awareness/sensitivity training for all professionals working with disabled.
- More availability of weight scales to accommodate wheelchair users; a requirement for an accessible treatment area in offices that have more than 2 - 3 practising physicians.
- More Doctors!
- I would like better access to information. I find it to be scattered and hard to find. For the first five years that I was ill, I didn't even know I could apply to CPP for disability benefits. It may have made the difference between our losing our home and not.
- There needs to be a central location where anyone with any kind of disability can go to get information--and we should not have to dig and dig for it because, often, we just do not have the energy for that kind of searching.
- Better hours as in later hours – say until 21:00 hours.
- X-ray, cat scan, MRI, and gynaecological examinations should be available for people in wheelchairs and transfer teams should be available at all facilities. Earlier detection of diseases like cancer would save money in the long run --there should be more access for the poor and disabled for important tests—A person shouldn't have to wait for months if there is a chance that they have cancer or some other serious disease. The tests should be available quicker and access to these tests not limited to the wealthy.

The Need for Change

Importance of Services and Improvements Needed

The following section addresses the needs and what people with disabilities deem as important to barrier-free access to health and medical services in Alberta. The highest choice for *Very Important* was for establishment of medical services that are appropriate to the needs of the patient. Survey participants expressed the importance of accessible medical exams, accessible entrances at medical clinics, parking stalls, and accessible and reliable transportation to and from medical appointments.

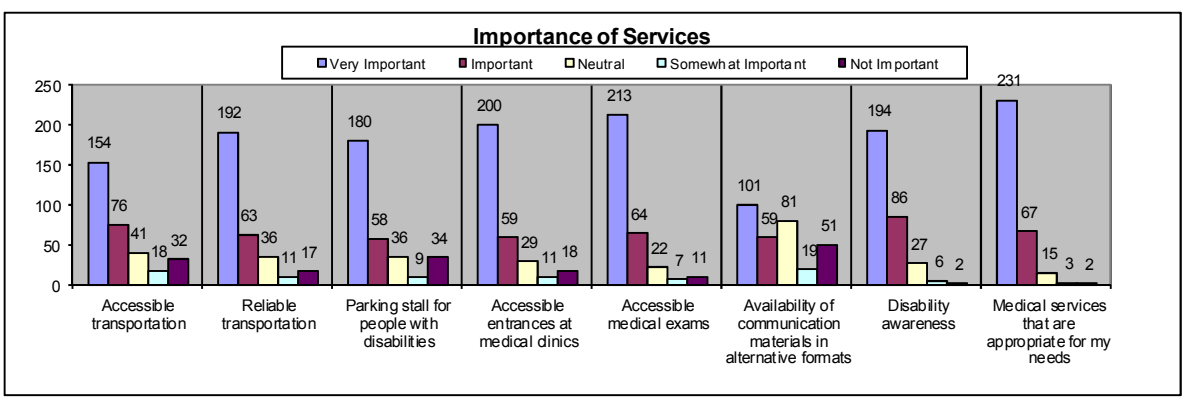


Figure 106: Importance of services

Participants also pointed out that disability awareness is very crucial for the establishment of barrier-free medical services in this province. Many stated that it is because medical personnel do not have knowledge about all disabilities so disability awareness will create two-way communication between the patients and their doctors.

Personal Experiences

The following statements were stated by the survey participants:

- My biggest concern is the poor washroom facilities and access to them especially in restaurants and in some offices. There are way too many doors to get in, too few with automatic door buttons, toilets that are too low (they all need to be 19 inches high, bars are often impeded by toilet paper dispensers.
- Service in rural areas is horrendous for people with any form of disability. The facility and services are not friendly, and the staff are uneducated or impatient with patients who are disabled. The doctors themselves are uneducated and arrogant in their practice. They seem unwilling to make proper referrals; rather they choose to make the patients undergo unnecessary testing, or incorrect diagnosis, or just not help them.
- Just because I have a disability, doesn't mean my time is not as valuable as an able bodied person and I like to take my turn in order also.
- The more severe your condition, the less availability of services. Unfortunately, the more severe your condition, the more important it is to have ongoing care so your needs escalate to requiring hospitalization. Then it gets really expensive!
- I'm not satisfied with my current physician but am reluctant to leave because it's so hard to find anyone else accepting new patients. There need to be more physicians (GPs and specialists) available in Alberta. Physicians need to be aware there are explanations for symptoms and not be so quick to assume that if they haven't been able to find the cause then it must not exist.
- Medicine is an art based on science. If multi-disciplinary teams were used, perhaps this situation would not arise so often. I've discussed my experiences with others who have chronic health problems and struggled to obtain a diagnosis and their experiences were far too similar to my own. That is, referred to multiple specialists who may or may not send test results back to my GP but who never speak to one another. These people then decide that when they can't find an explanation - the symptoms must be imagined - thank goodness for MRI's or I'd still be making the rounds to specialists. I'd like to see them go through a similar experience and see how they feel - perhaps medical schools should introduce them to this more with case studies that address the consequences of "no diagnosis" for years.
- Honestly I wouldn't know where to start. Whether it's a dentist, a physio, a doctor, testing and evaluation, there is ALWAYS an issue related to accessibility and therefore having to settle for LESS services than able bodied persons, and then there's the attitude of professionals/technicians of just not knowing how, or even a willingness, to address the needs of persons with disabilities.

- Communication access is usually very poor with staff other than my own doctor who I have trained. In most other public facilities it is a nightmare. There was not much provision here in this questionnaire to answer questions related to hearing issues! In particular for hospital stays!
- Printed information materials and/or instructions for procedures are useless to me as I am blind.
- At DynaLife clinic, they sometime call for my name without their noticeable with my deafness. It happened once or twice I missed my appointment and waited for a 1/2 hour or late. Tell them to write down what color of jacket or clothing a deaf person wears while waiting.
- Finding a GP who understands my disability has been a nightmare. I have gone to several who don't understand disability and will not make the effort to do so. Having advocates to access the proper services is very important. Sometimes it is 'who you know'. I also live on AISH (low income) and feel that I am not able to access things that will help me because there is a cost (i.e. acupuncture, massage therapy, supplements etc.
- I've likely said enough as it is. We have some superb physicians but generally by the time you have gotten to know which are which, they are either no longer taking new patients or have moved away or retired or have switched to doing research & limit themselves to only those persons who fit into the criteria of their research.
- Not enough awareness, or financial support of alternative traditional medicine, such as holistic medicine practiced by other cultures.
- In Emergency one doctor said "Saw you last week --seeking drugs? You have Munchausen Syndrome!" Family Doctor angry and confirmed NO MUNCHAUSEN SYNDROME but Capital Health refuses to remove it from hospital medical records. Now whenever I go to Emergency--even with broken bones--told hurt on purpose and NO PAIN KILLER cause I am addict--all because of that one doctor!! Every time.
- More closed captions! Figure out how to fix the bus calling to see how many minutes. Deaf people can never call.
- Generally I am very happy with my medical service from a general health perspective. Regarding my health conditions. Much better awareness and treatment options for these conditions.
- Dr's not very familiar with developmental disabilities and not aware of autism and personal space issues.
- I feel I have been lucky with the medical care I have received.
- I have had no success with treatment of my severe chemical sensitivities; one Dr. even suggested I see a Naturopathic Doctor. No one can explain why this has happened to me or provide me with the support I need.

- There are no mental health services for people with a DID diagnosis. If you are very lucky someone may become sympathetic and take your case but a lot of people get some stability clinically but they are generally left to their own devices to cope after a time without the proper resolution of the treatment. There are no diagnostic facilities for very large people or disabled people who need tests that are able to be used comfortably and safely. My worst experiences are having to purge my body with laxatives for an abdominal CT scan because my doctor told me I would surely fit in the machine and luckily the tech let me try the machine before I swallowed the isotopes. I had to go home without the tests and in tears. I broke a stool when I could not get up on an exam table for my last genecology exam. I was given an x ray for severe arthritis where I had to stand and could not stand well. I was in absolute pain and was told I could not take even one minute to rest because there were people waiting. I did remain in the room a minute because I simply could not move and luckily was out before the tech returned with the next arrival, but I was in pain for days. Nobody summoned the caregiver to help me. I have never had proper access to treatment for my mental health issues and this is like surgery without anaesthetic. I wanted to say that my providers were at least kind, but they allow this type of neglect to perpetuate itself, so is this kind? Is this professional? Is this nice? People with disabilities are denied proper care every day. One of my friends had booked a transfer team and they were not present when she arrived at the appointment as promised. Though she had spina bifida from birth and has never walked, they said "Can't you just jump up on the table?" There is a lot of talk about "people taking responsibility for their health" yet the disabled are blamed for the inability to take care of theirs.

- There is a lot of prejudice doctors against patients with a diagnosis of ME/CFS and FM. I've run into doctors that won't take you if you mention this diagnosis. I've met doctors on the phone that indicated that I have a mental illness without even speaking with me. Most doctors have never heard of these illnesses or pretend they have but know nothing about it. My GP told me "Don't go there. Don't even say those words," when I told her what I believed was my diagnosis. I was desperate to go to work and my GP with a special interest was out of town. I then went to many other doctors and I saw a specialist when I told her about my problem. We made a deal is all she would do. I had to commit myself to physiotherapy everyday for an hour for a month in exchange for 1 month off work.

- My Doctor is excellent. He has been my primary physician since I was 2 years old and now I am 19, but I am grown up now and it is time for me to find a new primary care physician. There doesn't seem to be anyone who is willing or able to take me on as a patient and give me the services that I need.

- Strict policy for providing ASL interpreters in hospital settings.

- Being told that once I am over 17, will have long waits and harder access to procedures and testing.

- I was suicidal and if it were not for my GP's "connections" it would have been a four month wait to see my Psychiatrist as it had been a year since being there (was not

required). I had an intended "date" of my suicide as March 21st. The referral was sent to the Mental Health Clinic at Northgate as urgent and I was contacted March 26th with the first available appointment being May 20th. Only advice given was "if it gets bad enough go to Emergency."

> Alberta should take bits and pieces of other countries medical procedures, and successes and put together the best health care system. - *Comment from a survey participant*

Conclusion

The results show that individuals with disabilities have unique needs to be addressed by the Alberta health care system. Generally, people are satisfied with the medical care they receive; however, the personal statements of the survey participants show that the system has many barriers for people with disabilities. Inaccessible medical clinics, inappropriate medical equipment, and long wait times are just a few of the many issues brought forward by the participants.

It is imperative to affirm that survey participants support the health professionals that offer and provide services; however, they perceive the health care system as flawed. Health professionals have no other choice but to implement the policies and procedures required by the Government of Alberta.

Participants are aware and acknowledge that no general practitioner will have knowledge about all disabilities, so they recommended better communication and relationships between GP's and specialists.

Participants recommended that the Government of Alberta support physicians and create a means for medical offices and medical equipment to be made accessible for use by all.

Disability awareness is another area that the survey respondents felt needed improvement. Conducting disability awareness sessions on a regular basis to health and medical professionals will create understanding about the various disabilities and the needs of patients with disabilities.

Survey Results for People with Disabilities: Survey Findings According to Disability Categories

Introduction

This section of the report presents the findings from the surveys filled out by people with disabilities according to disability categories, which were identified as the following:

- Hearing
- Seeing
- Speech
- Pain
- Learning
- Mobility and Agility
- Memory
- Developmental
- Psychological (mental)
- Multiple Disabilities
- None

Detailed results for each disability category can be viewed in Appendix IV.

People with Disabilities: Hearing Impairment

Twenty-two individuals (4.74%) who participated in the ACCD Barrier-Free Health and Medical Services in Alberta Survey identified themselves as Deaf, Hard of Hearing or Hearing Impaired.

> I am healthy in every way except my hearing and self esteem, I feel as a person of color and with hearing problem I can't get into good jobs or into college, it feels like a challenge every time I wish to go get an education or a good job. - *Comment from a survey participant*

The majority (45.45%) of the participants with hearing impairments are between the ages of 31 to 50, and 86.36% of the participants are female. Nineteen of the 22 participants declared living independently and only one (4.54%) declared that he or she is unable to work because of his or her disability.

> There are jobs that are perfectly available for me but other people don't think so. And there are jobs that I cannot do, but the things I can do, I am very good at. - *Comment from a Survey participant*

From the 22 individuals, 17 (77.27%) stated that they have a regular doctor (general practitioner) who is familiar with their disability. The average length of time the general practitioner has been their doctor is 12.26 years.

The results from the questions that ask about physical accessibility of the medical clinics and provision of services show that Survey participants with hearing impairments generally

answered *Not Sure* or *Not Applicable* to the questions that probe the physical accessibility of the clinic and the equipment.

To the question *is there an amplified communication system or device with volume control at the reception desk*, 6 (27.27%) answered *No* and 10 (45.45%) marked *Not Sure*. *Is there a TTY for use to make phone calls* was the following question and 82.35% answered *No*, and 64.70% marked that the staff are not knowledgeable using a TTY when contacting patients with hearing impairments. The next question *if needed, do the staff arrange for sign language interpreters in advance,* only one participant stated *Yes* and 6 stated *No*.

The following are some of the issues that were brought forward by patients with hearing impairments, when accessing health and medical services in Alberta:

- I really don't know because we never talk about my hearing loss, just once or twice. I get a lot of ear infections which he knows about and gives me antibiotics. But the specialist I went to see years ago I really didn't like him.
- For my yearly check-up, I called to make an appointment that will be held maybe in 3 or 4 months. My family doctor is really good but apparently she is fully booked easily.
- Because by the time the appointment comes around I don't need the doctor any more, the problem is either solved. Or I just end up going to medic center where they just don't do nothing just fill medications. Wasted time really.
- I mainly communicate through writing; however most Deaf patients prefer to have ASL interpreters. Hospitals and some doctors do not accommodate such critical communication access AT ALL.
- Waiting times are too long!
- Communication access is usually very poor with staff other than my own doctor who I have trained. In most other public facilities it is a nightmare.
- At DynaLife clinic, they sometime call for my name without their noticeable with my deafness. It happened once or twice I missed my appointment and waited for a 1/2 hour or late. Tell them to write down what color of jacket or clothing a deaf person wears.
- I was hospitalized for 2 1/2 months recently and I had a very bad experience there. The nurses tried speak to me through masks and I could not lip-read them through the masks. They got mad at me.
- We are in dire need of full time interpreters for the Deaf in the hospitals.

> Tell me what my options are. - *Comment from a survey participant*

The major issue for Albertans who are hearing impaired is not having Sign Language interpreters available for communication during medical care. Not having ASL interpreters represents a barrier to accessing appropriate health and medical services for Albertans who are hearing impaired.

It is not only when people with hearing impairments visit their general practitioner that they need ASL interpreters, but also when they access mental health counselling, dental care, and home care. The situation is even worse when Deaf or Hard of Hearing individuals are in the hospital and are unable to understand what they are being told or what the diagnosis is. Many will try to speechread but medical personnel sometimes speak from behind computers or with their backs turned. Writing as a means of communication is not always acceptable to individuals who have hearing impairments.

ACCD asked the survey contributors to provide solutions on how the system can operate better according to their unique disability needs. The following statements describe their personal perspectives for improvement of the Alberta health care system:

- I think it needs to be more productive, especially with seniors if they go there for more than one thing then they should be able to talk about everything in one sitting rather than going there over and over again. In long run it would cost less to medical system.
- Capital Health needs a blanket approach for ASL Interpreting Services...including psychiatrist and psychological assessment and long-term counselling...especially HOMECARE assessments for Deaf Seniors do not often include ASL interpreters!
- In regard to accessible through the entrance and the examining room.
- Full time interpreters for the Deaf in the hospitals!!!! And available at any time.
- Customer service by doctors and medical personnel is the biggest issue - in any other business the current level of customer service would not be tolerated. If doctors and medical personnel were paid based on customer service, it would be a drastically different system.
- I would like to see a doctor in few days of appointment rather than waiting few weeks and then forgetting about the problem. Able to discuss everything in one sitting.
- If they do not have a TTY, they can use a fax machine instead.
- Less time waiting for my appointment. Immediate access when emergency especially at the clinic or hospital. Medical people need to take some basic sign language rather than pulling or pushing me around.
- Full access to ASL interpreters.
- Automatic hiring of ASL interpreters for hospital rounds!
- Correct days of appointment, they give you one date and then they don't make the appointment and you show up and there is no appointment made wasted time and money.
- Most of Doctors are well respected but at the clinic or hospital - nurses and staff need to improve their mannerisms toward deaf people like me.

- More closed captions! Figure out how to fix the bus calling. Deaf people can never call.
- Strict policy for providing ASL interpreters in hospital settings.

The recommended solutions undoubtedly indicate that it is necessary to improve communication between patients with hearing impairments and providers of health and medical services. Medical professionals and staff should have knowledge about tools that can be used to communicate with individuals who are Deaf or Hard of Hearing, and to know how to book ASL interpreters. Without appropriate communication methods, many Albertans will remain isolated and unable to access appropriate health and medical services. Removal of these communication barriers will improve access to barrier-free health and medical services in Alberta for Albertans with hearing impairments.

People with Disabilities: Seeing Impairment

This section reports on eight individuals (1.72%) who identified themselves as blind, visually impaired, or having eyesight issues. 50% were male and 50% were female. Six participants (75.00%) marked that they reside in urban locations and all eight contributors (100%) live independently in the community. Some receive care support from family and friends. Five of the eight participants declared their health as *Good* and only one as *Poor*.

Several issues were raised by Albertans with seeing impairments, such as appropriate signage in buildings, transportation, and communication materials in alternative formats.

For Albertans with seeing impairments unsuitable transportation to and from medical appointments signifies a major barrier to accessing health and medical services. One participant stated that the "City of Airdrie provides a special needs bus for which I pay to take me to my appointments" but the service is never on time. Many pointed out that they depend on "rides from family and friends." Here are some additional issues with transportation:

- I am often late. Not so much so that the buses run late but the routes seem to change often and I regularly end up on the wrong bus at the wrong time. I will say that the bus drivers are very nice and helpful getting me back on track.
- Edmonton Transit/DATS policy dictates up to a 1 & 1/2 hour window after pickup to reach a destination. If you include the 1/2 hour pick up window that gives a potential travel time of 2 hours. While this is a worst case scenario and DATS usually picks up and drops off well within the window, it makes it difficult to meet appointment times and causes difficulties with employers and care givers. Regular Public Transit is not practical for Blind folks based on safe transit to most medical facilities.
- It can take longer if there are others on the bus who need to be taken to a different destination than mine.
- Appointments have to be on Tuesdays or Thursdays as the bus from Airdrie only goes to Calgary on those two days.

Lack of or inappropriate tactile signage at medical clinics and hospitals causes many Albertans with visual impairments to have difficulties navigating accurately between services and offices.

- Many buildings housing medical, dental, social services have poor or no tactile signage such as elevators with no Braille markings, washrooms with no tactile gender indications, and office doors with no raised numbers. Stairwells, which are a good alternative to elevators, are not easy to find.
- Often services are housed in different parts of the building or in different locations around the City. This leads to accessibility and transportation concerns.
- Plenty of clinics are not accessible to wheelchairs and many elevators do not have talking indicators.

One participant pointed out that her general practitioner does not assist her with issues related to her vision, and she has to make appointments with a specialist for any vision related issues.

- I have a regular doctor (general practitioner) but I do not consult with her regarding disability related issues. I have a specialist I see annually regarding my vision.
- Wait times are an issue especially when you take into account travel times to and from appointments.

Although the Government of Alberta passed the Service Dogs Act[313], many facilities and businesses still practice discriminatory practices against guide dogs used by individuals with vision impairments. Long wait times can cause discomfort to the animal and this can cause various issues for the individual.

- I use a service dog and his care and comfort is an issue during long waits at the Emergency Ward. I have also experienced an isolated incident of discrimination regarding the use of a service dog within a Doctor's office.

Accessible communication methods and alternative formats are minimal to none. Technology used by Albertans with vision impairments is not being utilized by medical institutions. Referral forms are given in print format rather than electronically or in Braille.

- No accessible appointment reminders - i.e. email text message, etc.
- Printed information materials and/or instructions for procedures are useless to me as I am blind.
- Referrals are not sent electronically for blind people using Adaptive Technology.
- Prescriptions and usage instructions are not accessible.
- Sometimes I feel the doctor rushes me through because he is running behind schedule.

[313] Province of Alberta. (2007*). Service Dogs Act*. Retrieved on January 15, 2011, from http://www.qp.alberta.ca/documents/Acts/S07P5.pdf

- Example, it seems a waste of resources to go to the Dr. for a simple prescription renewal and not be done over the phone if applicable.
- Information about these services or results are never in alternate format this is also true of preliminary do's or don'ts required before the test. Assumed that husband will read printed information.
- The only time I have ever received information in alternate format was from a weight loss specialist and that took some time.
- Everything is print based.

> I have had good medical care in Alberta; but I enjoy reasonably good health and have not had to access "out-of-the-ordinary" basic services. I do fear that if I did have a major health concern, I would not be able to access the information I require privately because it would not be in alternate format. To date, I have been comfortable having my husband read this information, but I might not always have this luxury, or in some situations, might prefer to have the information more privately first. - *Comment from a survey participant*

ACCD asked the survey participants to provide solutions on how coordination of the health care system can function better according to their unique disability needs. The following statements describe their personal viewpoints for enhancing the Alberta health care system:

- Better signage on doors and elevators (for the blind).
- Accessible information in alternative formats.
- Let me sum up with the following: Universal Access & Barrier Free Design!
- As long as it still remains a public system! I would rather keep what we have then to go to a privatized system.
- More awareness of disability related issues.
- Proactive approaches to care rather than reactive.
- Treatment of the whole person (listening and taking into account everything the patient says, they are the expert on how they feel and what they are experiencing).
- Accessible entrances i.e. sidewalks and indicators for doors, particularly at the diagnostic clinic.

The suggested solutions unquestionably point out that it is essential to establish appropriate transportation, accessible medical offices and hospitals, and alternative communication methods between patients with seeing impairments and providers of medical and health services throughout the Alberta health care system. Disability awareness and training will assist medical professionals to understand the unique needs of Albertans who have seeing impairments. New technologies should be utilized to improve communication. Tactile signage in buildings should be implemented in ways that will assist individuals to find the

right place. Removal of these barriers in the health care system will create the grounds for barrier-free health and medical services for individuals with seeing impairments.

People with Disabilities: Speech Impairment

One individual (0.22%) identified as having voice disorder and speech impairment. The participant is a female, living in a rural location, employed with income of less than $20,000. The participant depends on her family for care and has a regular doctor (general practitioner) who is familiar with her disability, but who has been reluctant to help her to have her needs met.

This survey contributor stated that her health is good, and she has not been referred to or accessed any diagnostic health services within the past year. In order to access her regular doctor, she has to travel more than 60 minutes. According to the survey responses, she reported that the doctor's office where she receives health and medical care is physically accessible, but there is no height-adjustable examination table or chair. In addition, the doctor's office does not provide sign language interpreters in advance or information materials in alternative formats.

The survey participant with a speech impairment marked that the health care system in Alberta needs *minor reforms*. For this participant, it is important to establish a reliable transportation system, make communication materials available in alternative formats, and provide medical services that are needs oriented.

According to the survey responses, for an individual with a speech impairment, it is vital that the system be reflective of his or her unique medical needs and that doctor's offices provide alternative communication methods. Proper communication is crucial for the right diagnosis and treatment, and without proper communication, Albertans with speech impairments will continue to experience barriers to health and medical services.

People with Disabilities: Pain Impairment

This group of 41 individuals (8.84%) identified chronic pain conditions such as fibromyalgia, chronic pain, arthritis, and various other disabilities that the participants described as pain related. 53.65% of the participants in this group are between the ages of 51 to 70 and 85.36% are female. Twenty-seven live independently and two in supportive living. Eleven of the participants have declared that they are unable to work because of their disabilities. Three of the 41 individuals are not able to find a regular doctor. The average length of time with their current general practitioner or doctor is 7.10 years.

Individuals with impairments caused by pain experience various barriers when accessing health and medical services in Alberta. One occurring issue is the inability of medical personnel to understand their disability/disabilities and offer appropriate therapies. One participant stated that services are accessed in Regina because the services are not offered in Alberta.

- I also see a neurologist in Regina to be checked and to have my intrathecal pump filled with pain medication.

- My general practitioner is reluctant to help me have my needs met. I feel he belittles my concerns and is too busy to follow my health.

Lack of sufficient appointment times and wait times represents another challenge for individuals with pain impairments, because of the multitude of symptoms and conditions.

- I feel rushed. He does not give value to what I am saying and I feel like he tries to speed up my visit because there is a waiting room full of people.
- Not enough time for my appointment
- Many times, the doctors are rushed and only allocate a certain time period. If you have more issues to discuss it is generally recommended that you make another appointment which is not very effective depending on the issues and having to wait again to access another appointment time.
- Inappropriate waiting times (usually months and months) to get appointments to see a Specialist or accessing certain medical procedures/tests in a timely manner.
- The allocated time is far too short. However, my doctor almost always gives me much more than the allocated time--which must make him run late for other patients.
- Not enough time to converse about other medical issues besides the particular one the appointment is for.

Transportation methods and distances also represent a barrier for people with pain impairments, as the following statements point out:

- My husband must drive me to appointments. I am too ill to drive, take public transit, or even tolerate a taxi.
- Even when asked to drive slowly and carefully due to my illness, drivers go too fast and turn corners too sharply. My body cannot tolerate the jostling. Also, taking a taxi home from the doctor's office may require me to wait longer than I can manage.
- Where public transit stops are, it’s a long walk to the doctor’s office, and walking is very difficult.

Individuals with pain-related disabilities stated that medical professionals and staff lack disability training and awareness about various disabilities such as Fibromyalgia, chronic pain, and environmental-related pain conditions. The following statements describe the lack of disability awareness:

- They have very little knowledge of Fibromyalgia and Chronic Fatigue Syndrome. Although both have been listed in the WHO list of diseases for two decades, these diseases are woefully misunderstood by most medical staff.
- The staff are woefully uninformed about FM/CFS. Often, these appointments are an ordeal because the staff is impatient or uninformed about my limitations. Even when I tell them, many tend to be almost indifferent. I don't think it's intentional; I think it's a

matter of their not being properly informed or trained--and, of course, they are under significant pressure due to cutbacks.

- I have spent many hours waiting in emergency for what, in one case, turned out to be a life-threatening illness. I was sent home 3 times after a total of 24 hours of waiting in ER. It turned out that a main artery was about to burst. Luckily by the time it did, I was in the hospital.
- There are very few doctors knowledgeable about environmental health issues.
- The doctor is good, but the staff need a lot of training.

Inability to find a doctor is another barrier that is experienced by this group. Many stated that it is because of their disabilities and others stated it is because there are no doctors in the area where they reside, as the subsequent statements illustrate:

- It has been well over a year and a half as I cannot find a doctor, and the closest one I would be accepted at is one hour and forty five minutes away.... way to far to drive for a regular check-up.
- My doctor fired me right after my diagnosis of Fibromyalgia with no reason given. I was told no other doctor at that clinic would take me on as a patient either. I had been a patient since 1997 at this clinic.
- When my husband retires, we will lose our GP because this doctor is employed by the Health Center at the University where my husband teaches. We have been looking for five years for another doctor, but have not been successful. Most are not interested in or willing to take on an FM/CFS patient. We are scared to death of losing our family doctor. It's another reason my husband cannot retire.

Physical inaccessibility of clinics and diagnostic imaging technology embodies discomfort when accessing medical care for individuals with pain conditions, as some survey contributors pointed out:

- Some places are not willing to help you move or stand or are not wheelchair friendly, too many people crammed into a little space or giving me no access in at all.
- I'm also my extremely claustrophobic, so MRI's are inaccessible to me.

This group of individuals also expressed that additional health-related costs represent barriers to health and social-based services:

- The cost of getting forms signs (i.e.: special needs bus pass, Disability placards) at the doctor's office is very expensive ($60.00 for each form) for seniors who are on fixed income.
- Upon arriving at my appointment for my mammogram I get a card to fill out that says for an extra $40.00 I can have a better image done by computer, to me this is a insult to a breast cancer survivor, and to a patient that my first mammogram missed my breast tumour 4 week earlier, so this upsets me greatly.

> Soon, I will have to switch doctors due to retirement. I have known this day is coming for several years and have made many attempts to find a new doctor. They are either too far away or unwilling to work with me. My current doctor and I have developed a treatment protocol based on treatments developed in the USA, but no new doctor will continue the treatment without tinkering with it (which makes me very ill for months or years). I am threatened by their ignorance and unwillingness to listen. - *Comment from a survey participant*

Survey participants were asked to provide solutions of how the health care system can function better according to their unique disability needs. The following statements portray the personal viewpoints for improvement of the Alberta health care system.

Hiring and treatment of medical professionals:

- Treat nurses and other health care professionals with respect. Stop making them work split shifts and part-time.
- Overhaul the hierarchy in the hospitals. There are too many middle managers with no health care experience.
- We are losing skills nurses and technicians because of poor working environments.

Preventative health care:

- I think that more preventive and especially immediate care of illness or injury would prevent many conditions from becoming more serious and costly. Waiting times are too long in emergency and for tests and specialists. I think there should be regular mandatory reviews of medications for those with complex health needs.
- Stop following the drug model of care, and start incorporating money-saving treatments such as nutrition, massage, chiropractic, and other "alternative" therapies that are more effective and cheaper than drugs and surgery.
- Really the health care system costs have not risen much in many years, yet it is blamed for costing so much. It needs to be rejuvenated with funds and a push is needed for more holistic, natural and home care.
- I would like to see clinics that utilize teams. Doctors, nurse practitioners, pharmacists etc. I think a lot of managing my illness could be done by a nurse practitioner.

Access to services and information:

- Access to additional services, less wait time, better care. I would like to be able to change/find an appropriate family doctor.
- Ability to access medical services more quickly and effectively when required. Increase handibus access by increasing the number of buses and operation dates for this service. Too many people are left with being unable to get to their appointments and that is not acceptable. You should be able to get to your medical appointments as required.
- I would like less wait times, better doctor-patient communication.

- I would like better access to information. I find it to be scattered and hard to find. For the first five years that I was ill, I didn't even know I could apply to CPP for disability benefits. It may have made the difference between our losing our home and not. There needs to be a central location where anyone with any kind of disability can go to get information--and we should not have to dig and dig for it because, often, we just do not have the energy for that kind of searching.

Disability training and awareness:

- Much better awareness and treatment options for these conditions.
- Specialists can diagnose CFS but will not provide ongoing treatment. Many family physicians feel the illness is "too complicated" and they do not know ANYTHING about it. They need to be educated to recognize the symptoms, as an early diagnosis is essential to allow for treatment and recovery. This will prevent a "disability" or lessen the impact.

The suggested solutions conclusively state that it is essential to establish efficient and appropriate access to services in the current health care system. For individuals with pain impairments, recognition and awareness about their condition seems to be the major barrier. Survey participants expressed that their doctor is not able to assist them or they are not able to find a doctor because of their condition. Coordination of services seems to be vital for this group of individuals in the creation of barrier-free health and medical services for individuals with pain impairments.

People with Disabilities: Learning Impairment

Twenty individuals (4.31%) that participated in the survey acknowledged having learning disabilities. Seventeen are between the ages of 19 and 30 and 68.42% from the 19 participants that answered this question are female. Eleven live independently and three in supportive living. 55.00% of the twenty participants are students and seven are currently employed. Four participants are unable to find a regular doctor and four have a regular doctor who is not familiar with their disability. One individual stated “don’t need a regular doctor,” as they consider their health very good.

Average length of time with the same doctor providing medical care for this group of survey participants is 5.46 years. Physical accessibility was described as not an issue for a few of the participants in this disability group.

For Albertans with learning disabilities, barriers in access to health and medical services are the inability to find a doctor that understands their needs, timely and appropriate access to services, appointment times, and communication with medical staff. A few participants pointed out that the inappropriate medical equipment used in the clinics or hospitals represents a barrier in their access to health and medical services, as these individuals have difficulties in understanding how to properly use the equipment.

Inability to find a doctor barrier:

- I am currently really struggling to find both a family doctor, but to find someone familiar with my disabilities is so hard. I even went to see the doctors at my school and they still don't know much, I had to go to the urgent care center for a meds consultation because there doesn't' seem to be doctors out there (that I have access to) that can help me.
- For the purpose of regular, long-term medical care, I have had problems finding doctor; therefore, I do not have a regular doctor who is familiar with my disability.
- Although I am not sure if Health Services in the Encana Wellness Center is a branch of Alberta health care, but in general, neither my husband nor I have access to a reliable family doctor. We have tried to capitalize on new physician openings and using the list provided by Alberta health care, but my experience has left me feeling completely overlooked.

Inappropriate access to services for individuals who live in rural areas and wait times for traveling diagnostic clinics to arrive in order to be able to schedule certain exams:

- Have to travel out of town. Ultrasound comes to Vegreville, along with bone density.
- Waiting for traveling mammogram.

Appointment and communication issues:

- I never seem to talk about everything I need to because I feel rushed.
- They don't seem to care they want to see me and get me out of the way as soon as possible.
- It is very difficult to develop trust with a doctor if they don't take what you are saying seriously and treat you with respect.
- One major concern is that in the wake of nursing/administrative staff in clinics and hospitals posting signs such as "abuse will not be tolerated", it seems patients are subject to relational aggression forms of bullying, are unable to stand up for their rights, and generally made to be powerless. I appreciate the need for such staff to assert their rights, but it seems less about holding patients to their responsibility to be respectful and more about saying "the nurse is always right, don't bother arguing".

Inappropriate equipment in clinics and hospitals concern:

- My weight is over 350+ so sometimes I'm too big for their equipment.

From the sixteen participants that responded to the question if the health care system in Alberta needs any changes, 62.50% responded that only minor reforms are need and 6 individuals answered between *Major Reforms* or *Complete Overhaul*. The following statements represent some of the suggestions that individuals with learning disabilities say about improvements to health and medical services for Albertans:

- Shorter wait times.
- More doctors.
- Doctors who understand.
- I would like to see a change in the way I am treated. I always feel like I am being rushed and that I am a burden.
- Be able to get in to them sooner, and have equipment that I can use.
- I understand funding is an issue, but the ability for people to get everything they need all in one place, at the same time, decreases the amount of visits needed and allows the doctor to adequately assess the nature of the patents concerns.
- Although the initial expenditure would be huge, it would save money in the long run if major communities were given a clinic which was able to perform blood work, x-rays, ultra-sounds, etc. (the basic, and most common laboratory/diagnostic services. Also, if these resources were more localized it would make them much more accessible to those with mobility issues, cannot/do not drive, etc.

For people with learning disabilities there are many challenges in finding a regular doctor and communication health and medical needs with medical professionals. Individuals living in rural areas are experiencing longer wait times as services are not established on a permanent basis but on the traveling clinics model. Without permanent, appropriate, and flexible services, individuals with learning disabilities will continue to experience barriers in their access to health and medical services in Alberta.

People with Disabilities: Mobility and Agility

From 464 survey participants, 171 persons (36.85%) identified as having mobility issues caused by injury such as spinal cord injury or degenerative disease like multiple sclerosis, muscular dystrophy or spina bifida. One hundred and twenty-eight are from urban and 37 are from rural locations. The majority (83.80%) of the 142 individuals responded that they live independently in the community, 9.15% are in a supportive living setting, 1.40% are in a lodge, and 2.11% are in a long term care facility. Forty-six individuals declared that they are unable to work because of their disability, and 11.69% are currently unemployed.

> Doctors only know so much about paralysis they probably only take a day or two on it. But mine is willing to learn and listen and between the two of us we can figure most things out. - *Comment from a survey participant*

From the survey participants with mobility and agility issues, 62.57% have a regular doctor who is familiar with their disability. Another 21.47% have a regular doctor who is not familiar with their disability, and 1.84% have difficulties in finding a regular doctor. Six individuals use medical centers to access health and medical services. The average length of time with the same regular doctor providing services is 8.77 years.

> I go to Beaumont to see my long-time family doctor. I rarely access the SCI specialists. - *Comment from a survey participant*

For Albertans with mobility and agility impairments, physical inaccessibility of clinics, hospitals, and medical equipment represents a major barrier when accessing health and medical services. Individuals are unable to enter doctor's offices or get on the examination table to have a test performed. Diagnostics tests like MRI's and CT scans are not accessible for individuals in wheelchairs who are unable to transfer on their own. The following statements describe some of the situations that individuals with mobility and agility impairments had to face while accessing the Alberta health care system:

- My doctor usually tries to work on me, but relies on me often to find some specialist services as there is nothing set up to overcome physical barriers as I am unable to transfer to exam/procedure tables.
- Even cancer association, Calgary's 311, and the spinal cord clinic were unable to give me advice where to access pap tests, due to barriers of being unable to stand. Spinal cord clinic physiatrist said "it's a problem for folks like you", and no solutions were given or physiatrist effort to assist with locating the service.
- I haven't had a complete physical since I was at the Mayo Clinic two years ago.
- I have only seen my general doctor a couple of time since leaving the hospital after my accident and both times, I did not have to get onto an examining table. I stayed in my wheelchair.
- My mom usually lifts me onto the table and helps me with my clothing. I can transfer myself from the table to my wheelchair.
- I find that when it comes to any kind of physical manoeuvring the staff are very hesitant and don't really know how to or what to do unless I tell them and I also have my own person along with me.
- My physician is part of a Primary Care Network. I think it's through the support of the PCN that she makes a home visit to do my PAP, since her office doesn't have an accessible exam table/bed for me to transfer to.
- I do not have my weight measured.
- My mom bought a scale used in industry to weigh animals. My home care hangs it from my track lift, and then hangs me from the scale. I don't think my doctor has ever asked about my weight.
- Mammograms are tricky. The machine will adjust to the height of a person in a wheelchair but often the room itself is not big enough to manoeuvre a chair around in. X-rays and CT scans have height adjustable tables so transfers do not require lifting, but I do need help sliding across to the table.
- Most facilities will NOT allow their staff to assist with transfers. Clients are told to bring someone with them. This is difficult for me as all my friends work during the day, and when I called Homecare I was told by my case manager that he was not allowed to authorize any staff to come with me, even to help me dress and undress.

- Bone Density (which everyone who cannot stand or walk should have) are the most difficult. This is because the machines do not lower and one must be lifted on to the table.
- I had fluoroscopy done and they could not do most of the test because it was designed for people who could stand.
- Small examining rooms.
- An MRI was booked at a time when there was not adequate staff to assist with lift so had to be rescheduled.
- Presently, I am having difficulty accessing medical devices (and medical professionals) to diagnosis and treat the conditions of malformed or blocked veins. A vascular issue that could potentially kill me or worsen my disability.
- The eye exam was difficult. It was hard to reach my eye to the place where the machine took pictures of it. We were able to do it after moving the equipment getting someone to help me hold my head in the right place.
- Most medical devices are too high and too firm. Very painful experience!
- I have had issues with the facilities not being able to accommodate a person that is larger and the equipment is not designed for people of all sizes.
- Need to work on making sure the automatic doors work and fixing the paved ramp up to sidewalk. Very poorly designed would not meet code.
- Wheel chair parking spots are way too small to accommodate a van with a lift. They should be wider.

The next issue brought up by this group was access to medical care and services and treatments for their unique disability needs:

- My doctor is reluctant to help because of the ethics governing his profession, the so-so called cost of the diagnostic procedure, the lack of necessary diagnostic equipment, and the indifferent procedure to treat the diagnosed problem for my disability.
- I believe I am the first paralysed patient my doctor has experienced, but he learns the intricacies of my condition as I learn more myself, and will refer me to specialists when presented with situations he does not feel qualified to treat in the best fashion.
- When comes to MS/epilepsy, specialist often want you to see GP. GP doesn't know a lot of things necessary to comply, including medications, general.
- I cannot get in to see him on short notice, and his staff do not seem to have any understanding that I'm not just a nag, but need to see him at times on very short notice. However, when I see him, for regular check-ups, he is knowledgeable and open to exploring all methods of addressing my issues.

- GP does not know the answers that the specialist would; however, a person does not see the specialist nearly as often.
- Always "fighting the system" to obtain necessary services because they are not set up for people with disabilities who don't fit into "the box". System is designed for reaction to health problems and not much attention to preventative and health maintenance.
- Disabled persons not considered as "team player" in health, and if I try to be am considered by some medical professionals as pushy or having a mind of my own.
- My doctor is in a Medi Centre and only works 3 days a week.
- My regular gynaecologist is great but the family doctor really didn't know how to do my pap smear. It is embarrassing to say that but she really had no clue how to handle a paraplegic during a gynaecological exam.
- I have never had the need to be transferred to the examination table. Most of my examination is done in my wheelchair
- Need transfer assistance- staff is reluctant/unable to do so.
- Couldn't find anyone that would give me ultrasound or mammograms. So still not sure what to do.
- Refused to give referral for angioplasty.
- The more severe your condition, the less availability of services.

> I feel very privileged because my doctor goes out of his way to treat me. he understands me...is in regular contact with my neurologist...always put my appointments at the end of the day so he can spend longer with me...does research for me. He too has M.S. - *Comment from a survey participant*

Regardless of disability type, the length of appointment times seemed to be an issue for everyone that participated in the ACCD survey. The reason for insufficient appointment times creates situations where patients are not able to receive proper treatments from their doctors, as the following statements point out:

- I don't think anybody gets sufficient time with their doctors anymore.
- Doctors always seem to be in a rush to move on.
- The doctors have to move the patients through quickly to make a reasonable living.
- In most cases, even with an appointment I have to wait in the waiting room for at least an hour. Then another hour in the examination room before the Dr. even comes in.
- My appointments are consultation only. The doctor can never do a hands-on exam as I'm in my chair all the time.

Finding a new doctor is another issue that impacts all disabilities and people express fear and concern about not being able to find a new doctor:

- GP soon to retire. Having trouble finding GP to accept new patients.
- I moved to Alberta in 2006 and can't find a regular doctor. I did find a doctor willing to take on patients but if I want to see him I have to wait at the clinic - usually at least 3 hours.
- My doctor is due to retire and works short weeks/months so finding a replacement will be a challenge.
- I still see my pediatrician.

In addition, lack of disability awareness represents a challenge in the relationship between the individual with a disability and the health care system in Alberta.

- He knows what my disability is, but sometimes forgets when he asks me to do a test. I will say and how am I going to manage to take that test. His response is oh right I didn't think of that.
- My doctor is sympathetic towards my disability and helps to a degree but does not really understand just how far my disabilities go. I understand this because he sometimes suggests my trying things which are outside the abilities of my disabilities: balance, strength, etc.
- I don’t feel the staff understand what I go through.

Without an appropriate transportation system, individuals with disabilities will have to wait longer to access health services. This situation is worse for individuals living in rural areas where there is a lack of many services. Traveling to other cities is the only way to access what is needed, as the following examples describe:

- No public transports within my town or to the big city (Edmonton).
- Specialized parallel transportation (ACCESS CALGARY) is undependable/not reliable.
- No public transit or access to handicap buses where I live.
- Most often unable to use handibus as they are heavily booked and run very limited hours (and don't operate past 4 pm or on w/e) in rural cities and outside areas.
- Specialized Parallel Transit is not reliable. Fortunately for me, I can access public transit and taxis. Others are not so fortunate.
- Depending on weather.

Sixteen individuals with mobility and agility impairments believe that the health care system in Alberta needs *Complete Overhaul*, 62 that it needs *Major Reforms,* and 56 agreed that it needs *Minor Reforms*. Two individuals stated that the system does not need any reforms. Here are some of their suggestions:

- Need to attract more doctors.
- Specialist and GP need to communicate better and GP's need to update knowledge of, needs of chronic diseases that are very common (i.e. MS, Cancer, etc.).
- I hesitate to say anything but "minor reforms" because people seem to use that as a justification for advocating private health care - definitely NOT what I want to see.
- I do think the best thing our health care system could do is have GPs and specialists work in groups so patient's information can be shared and faster diagnosis/treatment decided upon.
- Access to adjustable examination tables, being able to keep check of my weight.
- All medical facilities - especially privately owned labs should be totally accessible to all disabilities from staff knowledge to the equipment being used.
- The Health Care system must be patient driven, not cost driven. If funding is short, reinstitute AHC premiums. Have employers pay a 1% health care surtax, with an employee matching fund contribution.
- Any high level management must be removed, have health care professionals manage the system, not politicians or bureaucrats.
- I would like to see more clinics with nurse practitioners and other health care providers all working together with the doctors.
- All medical records including the chart notes should be on line and accessible to the patient and other health care providers.
- More focus on supporting preventative care. I have stayed out of hospital and off medications for over a decade, yet none of the alternative therapies or supplements I have used to maintain my state of health are supported - I'm on my own footing the bill, yet I've saved the government thousands of dollars by investing in my own health.
- Be paid for physiotherapy.
- The Liberation testing and treatment in Alberta and Canada.
- More accessible washrooms.
- Height adjustable examining tables, portable Hoyer lifts, roll-on wheelchair scales at government community health care centres and homecare support for personal care attendants to go to medical appointments.
- One location in each major centre to handle women's issues would be the most cost effective. It would have access, equipment and trained staff on site. It isn't reasonable to have such facilities at a regular doctor's office.

- Totality accessible diagnostic labs - knowledgeable staff when it comes to assisting the disabled appropriate equipment that can assist and accommodate people with disabilities.

The proposed solutions require a health care system where individuals will be able to access timely and appropriate medical services without being told that the doctor does not have proper training to treat their disability. Changes require policymakers to implement policies that will assure physical accessibility of clinics, hospitals, and diagnostic labs. Accessible medical equipment such as examination tables, weigh scales, MRI's, CT machines, and other medically necessary equipment should be purchased and available for usage. Disability awareness should be part of the training program for medical personnel and staff. A holistic approach to care has been requested by many project participants, and some participants have requested the approval of treatments that are not available in Alberta or Canada, but are available in other countries.

Without elimination of attitudinal and physical barriers in the Alberta health care system, many Albertans with disabilities will not be able to access appropriate care and may end up needing more costly medical care. The goal of the government of Alberta should be to create an accessible health care system and remove systematic barriers experienced by people with mobility and agility impairments.

People with Disabilities: Memory Impairment

Two individuals (0.43%) identified as having memory issues. One participant was male and one female, both residing independently in an urban location. One participant marked that they require care support but none is available.

One participant has a regular doctor who is familiar with his or her disability. The other stated that he or she has a regular doctor who is not familiar with his or her disability. For this group, the average time of the doctor patient relationship is 6.50 years.

Only one participant answered the question about the reforms to the Alberta health care system and pointed out that the system needs major reforms. In addition, in order to access appropriate and timely health services, the participant identified the importance of having accessible and reliable transportation to and from medical appointments.

The following statements are personal reflections of how the health care system in Alberta can be improved for patients with memory impairments:

- I believe that a public health care system can work if it is organized and structured to work. Health care costs money and that's life. Health care should be a fundamental priority.

- A better organized system that works for the inflow of patients.

For individuals with memory impairments, it is important to have a system that is connected and patient-oriented. Eliminating individual fragments and creating one unified health care system will eliminate barriers to health and medical services and decrease the cost of running the health care system.

People with Disabilities: Developmental Impairment

Eighteen participants (3.88%) identified as having developmental disabilities that have occurred prior to the age 18 such as autism spectrum disorders or brain injury. Seven participants are males and 11 are females. Seven live in urban and nine in rural locations and three of the participants are unable to work because of their disability, and 66.66% make less than $20,000 a year.

Twelve participants have a regular doctor who is familiar with their disability and one stated that they are unable to find a regular doctor. The average length of time the survey participants have with their doctor is 7.91 years.

For people with developmental disabilities, wait times represent a major barrier in accessing appropriate medical care:

- My community has 2 regular doctors who are busy and are too full for me, and so I see the visiting doctors when I need to see them.
- We have a walk in clinic from Monday to Thursday but line ups are extremely long.
- The Doctors are always running behind so that makes it hard for any others waiting. The Dr's are always in a hurry due to being behind.
- Medical services are too rushed and behind and a person never gets enough time to ask any questions or be able to cover all my needs at that time.
- During a hospital stay I developed foot drop and currently need to wear a brace for same.

When moving from child to adult services, individuals with developmental disabilities experience that the paediatrician has more knowledge about their disability/disabilities, and they tend to stay with their pediatrician for medical care and treatment:

- Recently, started to also see a developmental pediatrician who is gathering information about me.

Access to services has to be done with various accommodations as some individuals are unable to access traditional means of transportation:

- I have assistance by my community support worker to attend medical appointments as well as my job and recreational activities as public transportation increases my anxiety.
- Had to come in for a doctor appointment on the Greyhound when I was out visiting.
- There is no public transportation in the city other than taxi.

Communication is critical for proper medical care and few survey participants pointed out that medical professional and staff tend to use language that is not easily understood:

- I sometimes don't know what the words mean, or what I am supposed to do.

There is a lack of disability awareness and sensitivity training among employees of the Alberta health care system:

- People are always joking and somewhat teasing people with disabilities, not really sure how to handle them.

The eighteen survey participants with developmental disabilities proposed the following solutions in order to create a system that will be responsive to their unique needs:

- All my information would be somewhere in one place where different doctors could see it so I won't have to explain all about myself every time.
- Other than a better understanding of Autistic Spectrum Disorders, there's not a lot to be done.
- More doctors on staff. Diagnostic tests take forever to get in.
- Taking care of my needs and finding answers to my medical issues.
- Less wait time to see specialists.

The proposed solutions show that individuals with developmental disabilities need medical care with disability awareness and appropriate communication methods. Without sensitivity training medical personnel and staff will not be able to provide services that are necessary for the health and wellbeing of Albertans with developmental disabilities. These barriers need to be removed, and a more responsive health care system needs to be established.

People with Disabilities: Psychological (mental) Impairments

From 464 participants, 14 individuals (3.01%) identified as having mental health conditions such as schizophrenia, bi-polar, depression, post-traumatic stress syndrome, and other mental health related conditions. Twelve survey contributors were females and two males. Eight are employed and four are unable to work because of their disabilities.

Six participants have a regular doctor that understands their disabilities and three stated that their regular doctor is not familiar with their disability needs. For this group, the average length of time between patient and doctor is 5.85 years. Except for their regular doctor, psychologists and psychiatrists offer medical care to these individuals.

Survey participants with psychological impairments stated that mental health awareness is a major barrier in their access to health and medical services in Alberta. Doctors and staff do not distinguish mental health problems from situations like aggression or disobedience. Here are some personal perspectives:

- Mental disabilities receive less attention
- Moved from High River where I had a doctor, can’t find a doctor taking new patient in Calgary.

Critical and immediate care is sometimes a must for individuals with mental health illness:

- My family doctor is booked up months in advance and if I have an urgent need I have to go to a walk-in clinic.
- I only access my doctor (general practitioner) in relation to my disability. He is only available when school (university) is in session. Most of my other medical needs are addressed at walk-in clinics.
- Because my seizures are not fully controlled by mediation, if I have a seizure outside of my home, EMR is called. This causes me significant financial hardship because I have often been without benefits and never have enough coverage for ambulance service.
- There are no mental health services for people with a Dissociative identity disorder diagnosis. If you are very lucky someone may become sympathetic and take your case but a lot of people get some stability clinically but they are generally left to their own devices to cope after a time without the proper resolution of the treatment.
- For my GP-the Psychiatrist was a 4 month wait.

Inappropriate transportation is a challenge for this group of survey participants as well:

- Driven by a family member because public transportation cannot get me to and from work in a timely way. Maintaining employment has been challenging for me. I have had 7 employers in 7 years. I have been let go because I have had a seizure at work or because I have difficulty with memory because of my medication.
- The service is only reliable if you book right at the doorway in the case of a taxi; the handibus may not always be available or where I live they only may be able to go one way but not the other. I have also heard that the bus may get you there so late.

Inappropriate and inaccessible medical equipment is also an issue:

- I broke a stool when I could not get up on an exam table for my last genecology exam.
- I was given an x ray for severe arthritis where I had to stand and could not stand well. I was in absolute pain and was told I could not take even one minute to rest because there were people waiting.

People with mental health illness offered the following recommendations for improvement to the Alberta health care system in order to have an appropriate medical system that will respond to their unique disability needs:

- The health care system had just begun to adjust to regionalization and is now dismantling the process. Government needs to stop moving things around and around. Focus on SERVICE and treatment. INCLUDE and ACCOMMODATE people with disabilities.
- More doctors are needed.

- More respect from staff at diagnostic centres as they can be quite rude.
- It is unconscionable that disabled people are not being accommodated in things like MRIs and CT scans.
- ALL tables should raise/lower and there should also be clinics for people who are unable to physically disabled until ALL clinics and diagnostic test can accommodate them.
- Establish diagnostic facilities for very large people or disabled people who need tests that are able to be used comfortably and safely.

People with psychological (mental) impairments need effective, immediate, and appropriate access to health care. Doctors should not refuse patients based on their disability, and mental health awareness should be enhanced and implemented on a wider scale. People with mental health issues experience barriers in the current health care system, and the next step would be to eliminate these obstacles and create a system that is fair and equitable for all.

People with Disabilities: Multiple Impairments

Seventy-three survey participants (15.73%) identified as having more than one disability. The contributors acknowledged as having multiple disabilities that consist of combinations of two or more of the following: hearing, seeing, speech, pain, learning, mobility, memory, developmental, and psychological disabilities.

In this group, 73.97% are females and 82.60% are from urban locations. From all disability categories, this group has the highest percentage (48.61%) of individuals who are unable to work because of their disabilities. Thirty-four out of 67 individuals reported annual income less than $20,000 per year.

> 4 different part time jobs, I am frustrated to get one fulltime job. - *Comment from a survey participant*

In regard to having a regular doctor, the following information was compiled:

I have a:		
Answer Options	Response Percent	Response Count
Regular doctor (general practitioner) who is familiar with my disability	55.07%	38
Regular doctor (general practitioner) who is familiar with my disability but who is reluctant to help me have my needs met	10.15%	7
Regular doctor (general practitioner) who is not familiar with my disability	7.25%	5
Regular doctor (general practitioner) who is not familiar with my disability but is willing to work with me and help me have my needs met	17.39%	12
Problem finding a regular doctor (general practitioner)	4.35%	3
I use a medical center to access my regular doctor (general practitioner)	5.79%	4
answered question		69
skipped question		4

Figure 107: People with multiple impairments and having a regular doctor

The average length for patient doctor relationship for individuals with multiple disabilities is 6.80 years. Thirty-six individuals stated that their doctor sees their abilities rather than their disabilities. Sixty percent of the 60 participants that answered the question about system

reforms believe that the Alberta health care system needs *major reforms*, 21.66% stated that the system needs *minor reforms,* and 16.66% believe that a *complete overhaul* is needed.

> I am so wedged between the cracks in the system it's a joke. There is help for people with cancer, MS, "popular" diseases, workplace injuries, motor vehicle accidents, sports injuries, but once you have multiple traumas no one wants to look at more than one injury or how they interact. Also no one wants to deal with injuries caused by an assault. The waiting lists for pain clinics exceed the Statute of Limitations for pressing charges and getting help for an assault. This is madness. - *Comment from a survey participant*

For people with multiple disabilities, access to health and medical services is one of the major barriers, as the following statements reflect upon personal experiences:

- My doctor would like me to see my therapist once a week, however due to a lack of staff and large amount of clients I can only see her once every 3 weeks.
- Brain injury support is focused on rehab not on continuing care.
- We are trying to find appropriate care that covers our situation. Not many people are available in Cochrane, my husband's work hours vary (usually evening a weekend) and it's harder to get help in these hours. We have special needs child that needs care alongside me. We are having trouble finding care that fits our situation.
- Use medi-centre doctors and they will not help me with my AISH application at all.
- Family doctor of some 15 years dismissed us as patients; we now go to a medi-centre.
- I have a regular doctor who is a pediatrician. I should graduate to a general practitioner but have not found one who can provide the care that I need, so I keep seeing my pediatrician even though I am an adult.
- Have not had an exam due to not being able to access the examination table.
- I have not had a proper weight measure in about 10 years or so.
- I think the biggest issues are around getting onto and off of an x-ray table or exam table. Most of the clinics don't have enough space for wheelchair folks to manoeuvre around and also the rarity of lifting teams are a BIG barrier.
- I need someone to explain or translate on my behalf. They do not have someone on staff to translate for me. I cannot access medical assistance without support.
- Poor communication between clinics, some doctors and hospitals.
- Not enough doctors at Medi-centres; too long waiting times for Medi-centres and getting tests done and then finding out the results; not enough doctors who specialize in CFS (my CFS doctor has a 2 year waiting list).
- While doctor's office visits are not difficult to access, there have been times when the waits for special diagnostic testing (CT, MRI, EEG, DNA analysis) have been unacceptably long.

- Service in rural areas is horrendous for people with any form of disability.

> I am considering euthanasia. I am in so much pain and there's nothing the province will do except drug therapy. I can't afford massage therapy or acupuncture or anything that will help and I need flexibility due to the anxiety and other side effects of the pain. I feel there is no place for me in this world. Even my family has turned their backs (and moved to Utah, how helpful). - *Comment from a survey participant*

Disability awareness is also lacking according to people with multiple disabilities:

- I have a GP who is not familiar with my disability and speaks about me to my parents even though I am in the room.
- My doctor appears to have a lack of knowledge in the area of learning disabilities and mental health.
- No eye contact or patience in dealing with communication access.

One participant stated "I do not have the emotional and physical energy to do much of the searching, phoning, interviewing".

> When this child was young, her pediatrician called during the evening at home to announce that she was dropping this child as a patient because she was "too complex" and there wasn't enough support from the neurologist. This doctor left her patient without care during a period of change in medications - an irresponsible and unprofessional act. No follow-up was provided and no assistance given in finding a new doctor during this critical period. - *Comment from a survey participant*

People with multiple conditions and disabilities presented the following recommendations for the improvement of the Alberta health care system in order to have a more appropriate medical system that will respond to their unique disability needs:

- Where more time is needed, it should be given.
- Transportation needs to be easier to access.
- Nurses and technicians at hospitals need to be educated and more empathetic towards patients.
- The people making the decisions on health care are only concerned with the dollar amount, and don't know anything about the training and guidelines the staff follow daily to ensure patient care.
- Needs to have some sort of system of patient advocacy for those with disabilities who have problems with communicating about their symptoms as often taken as psych patients and receive inappropriate response from staff and paramedics.
- The psychiatric community as a whole must be made to understand that a person with developmental disability is to be valued as much as anyone else in society and the care given to them should be the same.

- I want a more holistic approach that emphasizes supports for wellness so maybe we don't need so many expensive treatments.
- Educating hospital staff on physical and mental disabilities; enough to provide working knowledge. Also the emotional trauma children with disabilities face; showing empathy.
- Shorter waiting times for certain procedures and tests.
- More lifting teams in place in clinics.
- Better access to primary care.
- More access to new treatments.

The survey participants that declared having two or more disabilities require a system that is responsive to the numerous needs they have as patients. Appointment times are insufficient because *one issue per visit* policy does not allow enough time to address the various problems. Doctors need disability awareness training and a better understanding about the pain that some participants experience. People with multiple disabilities experience various barriers to which they have offered some solutions. The system needs to adapt and eliminate barriers to appropriate health and medical services for people with multiple disabilities.

People with Disabilities: None declared

The category *None* is to some extent an anomaly as even though individuals wrote *None* as their answer, they answered some questions as they have a disability. In addition, numerous participants in this category did not answer many of the questions. From the 464 surveys, 94 individuals (20.25%) declared *None* to the question that asked for the participants to identify their disability/disabilities. The majority of the individuals in the *None* category have recovered from an illness such as cancer, or have symptoms that are occurring at intervals such as occasional seizures.

> As doctors come and go in my town, permanent staff keep new doctors up to date on my disability. - *Comment from a survey participant*

This group of survey participants expressed concerns regarding access to services, appointment times, and physical accessibility to buildings and medical equipment. Lack of appropriate and timely services is a challenge when accessing health and medical services, as the following personal statements describe:

- Mammograms are not done here except when a van comes through once a year.
- We have to travel to Edmonton to access services.
- Not a lot of privacy in front end of either doctors offices or entering emergency - you won't give out medical info but you sure have everyone broadcast it when we show up for appointments or help.

Appointment times are an issue because of not enough time for the extremely busy doctors to spend with their patients:

- I try to keep everything down to a minimum, since the doctor is always booked so far in advance, that it almost makes me feel bad to take up her time.
- 10 minutes appointments is not enough time and only being able to discuss one issue at time is inconvenient and caused frequent doctor's visits.
- I feel that I am always rushed and never actually looked at. Yes, they take your blood pressure and other vitals, but never really spend the time needed to assess.

Survey participants expressed concerns with the inappropriateness of the physical accessibility of buildings and medical equipment:

- The table for x-ray does not adjust up or down.
- Inaccessibility of devices using a wheelchair, lack of knowledge or skill of technician's part to provide assistance.
- Whether it's a dentist, a physio, a doctor, testing and evaluation, there is ALWAYS an issue related to accessibility and therefore having to settle for LESS services than able bodied persons, and then there's the attitude of professionals/technicians of just not knowing how, or even a willingness, to address the needs of persons with disabilities.

Survey participants were asked to present solutions that will enhance their access to health and medical services in Alberta and the following recommendations were provided:

- All hospitals and doctors' offices should have adjustable height tables.
- Allowing more time for appointments. Also to get in quicker to specialists.
- For all medical services to comply with both human rights and building codes as related to providing services to persons with disabilities (e.g. every office should have an adjustable height examination table, all staff should have disability awareness training)!
- Every Albertan deserves medical care, regardless of income.
- More spacious doctor's examination rooms.
- All medical building should be wheelchair assessable, if not then should be enforced.
- Alberta should take bits and pieces of other countries medical procedures, and successes and put together the best health care system.

For this group of survey participants, ongoing access to health care is crucial as these individuals are trying to practice preventative rather than reactive health care. If the system is not appropriately set up, then preventative and continuing care will not function properly and people will relapse into their previous conditions. All participants expressed the need for preventative care, not only through medication but also holistic programs. The government must take these recommendations into consideration if the goal is to have patients as part of

the health care team. If patients believe that there are other options to therapy than these options should be explored.

> I think we have a great health care system. Every time I have needed it, it has been there for me. - *Comment from a survey participant*

Conclusion

The personal statements reflected in this section clearly show the need for improvement to the health care system in Alberta. Survey participants were generally satisfied with the services provided; however, there is a need for change so the system can be more responsive to the unique needs of individuals with disabilities.

Site Visits: Accessibility Audits

Purpose

The purpose of this component of the needs-assessment was to conduct accessibility audits according to a pre-established audit tool and gather information about the accessibility of settings that provide and deliver health and medical services to Albertans. The intent was to compare various settings such as community health centers, physician clinics, and locations that provide diagnostic services, and present information that illustrates current access to health care services for people with disabilities at the audited sites.

ACCD submitted 41 audit requests to five health care services delivery setting types in the province between May 11 and September 20, 2010; however, ACCD only received permission to perform an audit from seven locations. The remaining number of sites declined to participate in the ACCD project. In December 2010, ACCD received a requested to audit three diagnostic clinics, which were completed in January 2011.

ACCD Accessibility Audits: An Historical Perspective

Accessibility has always been an immense concern to people with disabilities. Obstacles are being created by architectural designs that limit accessibility to individuals with mobility, visual or cognitive impairments.

For the Alberta Committee of Citizens with Disabilities, as a consumer-directed organization, elimination of barriers to accessibility is a priority. In 1988, ACCD developed an *Accessibility Audit Summary Checklist* – a tool that was designed to audit businesses and provide recommendations for removal of physical barriers for people with disabilities. This ACCD checklist was seen as a positive initiative by the Government of Alberta, which began funding the ACCD Accessibility Audit Program. Throughout the years, ACCD has built on this original checklist and revised its audit tool in 1998, 2000 and 2009.

Historical Perspective of the Development of the ACCD Audit Tool					
1941	**1988**	**1998**	**2006**	**2009**	**2009**
The Federal Government of Canada published the first National Building Code	**ACCD Developed an *Accessibility Audit Summary Checklist* based on the National Building Code**	**ACCD revises the audit checklist and creates the *Accessibility Audit Checklist***	**The Alberta Building Code 2006 was established.**	**Alberta makes revisions to the Alberta Building Code.**	**ACCD amends its audit tool to reflect the changes within the Alberta Building Code and establishes the *ACCD Accessibility Audit Tool*.**

Figure 108: Historical Perspective of the Development of the ACCD Audit Tool

The rationale for revisions to the code was the development of new standards related to new equipment utilized by people with disabilities. Below is a comparison of some of the changes that have occurred from 1988 until 2009 regarding accessibility code requirements:

Accessibility Area Requirements	1988	2009
Walk surface requirements	920 mm	No less than 1100 mm
Entrance door width	760 mm	800 mm
Vestibules between the wall containing in-swinging doors and the facing wall	Minimum of 1980 mm	Minimum of 1200 mm
Rams width	900 mm	870 mm
Drop off zone	3900 mm	1500 mm
Telephone built-in shelves depth	265 mm	400 mm

Figure 109: Comparison of accessibility requirements

In 2009, ACCD began work on the *Hotel Accessibility* project[314], a research initiative that measured building code compliance in a sampling of hotels throughout the Edmonton-Calgary corridor. This project garnered the attention of the Alberta Safety Codes Council, and ACCD now works with building code inspectors in the City of Edmonton, to help ensure that new construction projects are meeting the building code's barrier-free requirements.

ACCD Barrier-Free Health and Medical Services Audit Tool Sources

The ACCD *Barrier-Free Health and Medical Services Audit Tool* was developed from the following sources: section 3.8 (in addition, referencing sections 3.3, 3.4 and 3.5) of the 2006 Alberta Building Code, which deals specifically with barrier-free design for people with disabilities; the Hotel Association of Canada's *Access Canada Property Standards Manual*; and a paper titled *Making Our Offices Universally Accessible: Guidelines for Physicians*, which was published in the Canadian Medical Association Journal in 1997.

Alberta Building Code

With the exception of Ontario[315], all provincial building codes use Canada's National Building Code as their foundation. In 1937[316], the National Research Council (NRC) was approached by the federal government with a request to develop building code standards. In 1941, the NRC published the first version of Canada's National Building Code. Today, the NRC's Institute for Research in Construction oversees the development of the National Building Code, with revisions and additions occurring every five years.

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[314] Alberta Committee of Citizens with Disabilities. *Web Site*. Retrieved on December 10, 2010 from http://accd.net/html/what_we_do_projects.html

[315] Ontario Ministry of Municipal Affairs and Housing. *Ontario Building Code Web Site*. Retrieved on December 23, 2010, from http://www.mah.gov.on.ca/Page7393.aspx/userfiles/HTML/nts_4_27461_1.html

[316] National Research Council of Canada. *A Brief History of Canada's National Codes.* Retrieved on December 23, 2010, from http://www.nationalcodes.ca/eng/building_code_history.ppt

Provinces have the option of either adopting Canada's National Building Code in its entirety or modifying it to suit local or regional needs, which is the case with Alberta's building code. Alberta uses the National Building Code as its base document, but Alberta's Safety Codes Council and its technical sub-councils consult with municipalities and a variety of stakeholders to ensure that the Alberta Building Code meets the unique needs of the province. The Alberta Building Code is divided into sections that are specific to matters like plumbing, heating, and structural integrity, to name a few. Section 3.8 from the Alberta Building Code addresses barrier-free design building requirements.

Like any built environment designated for public occupancy, buildings in which health and medical services are provided must comply with the provincial barrier-free code criteria that was current at the time of construction, renovation, or change of occupancy classification. Older buildings that have not had renovations or a change of occupancy are not required to meet code updates or revisions. For example, if a built environment was constructed during the 1970s, and it has not undergone renovations or a change of occupancy, that building is not expected to meet any building code criteria other than what was current at the time of its construction.

Since the passing of the Alberta Building Code in 2006, there have been many challenges with the implementation of the Code's Barrier-Free Section (section 3.8) during design, construction, and renovation of buildings in Alberta. In 2008, the Safety Codes Council produced the *Barrier Free Design Guide*. "The purpose for this Guide is to provide an explanation of the intents and objectives of each Code, as well as to make recommendations that are viewed as best practices where accessibility and safety are concerns to people with disabilities and to seniors."[317]

Access Canada Property Standards Manual 2007

Access Canada was designed to assist hoteliers in creating a comfortable and welcoming environment for guests with disabilities and senior citizens.

In 2007, the Hotel Association of Canada released *Access Canada Property Standards Manual*[318], a publication that outlines four levels of accessibility, ranging from basic to optimal. Most of the criteria found in section 3.8 of the Alberta Building Code are found in *Access Canada*, but in many areas, such as signage, *Access Canada* goes well beyond barrier-free building code requirements.

[317] Safety Codes Council. (2008). *Barrier-Free Design Guide: Design for Independence and Dignity for Everyone*. Retrieved on December 1, 2010, from http://www.safetycodes.ab.ca/upload/docs/SCC-BFDG-FINAL-protected.pdf

[318] Access Canada. (2007). *Property Standards Manual*. Retrieved on December 23, 2010, from http://www.gnb.ca/0048/pcsdp/PDF/PublicationsWebpage/Access%20Canada%20Standards[1].pdf

Making Our Offices Universally Accessible: Guidelines for Physicians[319]

Dr. Karen E. Jones, physician and University of Toronto lecturer, and Dr. Itamar E. Tamari, a Toronto-area physician, produced a paper titled *Making Our Offices Universally Accessible: Guidelines for Physicians*, with the intent to provide guidelines to physicians to establish health service delivery that will be accessible to all their patients. The authors are members of a group made up of physicians and persons with disabilities who are working together to improve primary health care for persons with disabilities.

Because the Alberta Building Code does not deal specifically with doctors' offices or medical equipment, we used recommendations from *Making Our Offices Universally Accessible: Guidelines for Physicians*, to add to the *Barrier-Free Health and Medical Services Audit Tool.*

These sources represent current minimum code requirements and best practices in barrier-free design. Although many of the facilities are not required to meet current code or best practice standards, ACCD's audit tool is designed to measure the presence or absence of barrier-free design that a person with a disability requires in order to have equitable access to a public space.

Barrier-Free Health and Medical Services Audit Tool: Structure

ACCD's audit tool considers the following areas of accessibility:

- Parking, driveways and exterior walks
- Accessible entrances, doorways and doors
- Exterior ramps
- Handrails, guards, slip resistance, treads and risers on exterior ramps
- Handrails and guards on exit and exterior stairways
- Headroom clearance
- Interior barrier-free path of travel
- Corridors
- Interior ramps
- Handrails, guards, slip resistance, treads and risers on interior ramps
- Handrails on interior stairways
- Elevators
- Washrooms
- Water closet stalls and water closets
- Urinals
- Lavatories
- Universal Washrooms
- Counters
- Telephone equipment shelves and counters
- Drinking fountains
- Controls

[319]Jones, K. and Tamari, I. (1997). Making Our Offices Universally Accessible: Guidelines for Physicians. *Can Med Assoc J 1997;156:647-56.* Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1232828/pdf/cmaj_156_5_647.pdf

Criteria from each source are presented as a question, to be answered *Yes*, *No*, or *Not Applicable*. Questions answered *Yes* indicate compliance with a criterion, questions answered *No* indicate non-compliance, and questions answered *Not Applicable* indicate that a particular criterion did not relate to a particular area of the facility being assessed. The actual measurements are conducted according to the metric scale in millimetres.

Methodology

Forty-one medical facilities were contacted by mail on May 11, June 8, July 22, September 1, and September 20, 2010. Follow-up calls were conducted within a week after letters were sent to health and medical facilities. Of the 41 requests sent to medical facilities, there were 34 negative responses. Some of the reasons for negative responses included plans to move to a new, more accessible facility; approval denied by managers in Alberta Health Service; being too busy to participate, scepticism about confidentiality of the study, and general lack of interest.

Those who agreed to participate were interested in improving accessibility or curious to know how their sites measured up to accessibility standards. Each interviewed participant stated that he or she believed in the importance of making health and medical services barrier-free to all people.

The request from the three diagnostic clinics was initiated by the management body responsible for the clinics. They were interested in learning about the accessibility level of their diagnostics clinics.

Locations

ACCD conducted site visits at urban and rural locations. Because of the anonymity requested by the audited site, ACCD is not able to state the names of the audited locations.[320]

The Audit Process

For the purpose of gathering information for the ACCD *Barrier-Free Health and Medical Services in Alberta* project, the audit process included conducting interviews with on-site managers and site audits using the accessibility audit tool designed for this project.

Interviews with health facility managers

ACCD interviewed on-site managers at each audited facility, exploring the following:

- policies and procedures for accommodating people with disabilities
- disability training opportunities for staff
- transfer of patients from wheelchair/scooter to the examining table/chair
- written instructions for managing care at home
- written instruction for prescribed medications
- flexibility in appointment times and procedures
- personal opinions regarding current practice and service delivery
- personal opinions about the current health care system

[320] The ACCD letter requesting permission to conduct site audits can be viewed in Appendix V.

- personal opinions about perceived and experienced barriers to health care
- personal opinions about immediate necessary improvements.

Site Visits

The site visits consisted of conducting accessibility audits by using the ACCD Barrier-Free Health and Medical Services Audit Tool checklist.

Site Visits: Report of the Findings

ACCD visited ten sites that represent a variety of medical and health facility settings at various locations across the province. Managers and directors were interviewed and asked to respond to a series of questions about policy for managing people with disabilities, as well as their personal opinions regarding barriers and problems within Alberta's health care system. Upon completion of these interviews, ACCD staff members conducted audits, measuring built environments against the criteria in the audit tool.

The sites were rated according to the *Barrier-Free Health and Medical Services Audit Tool*, the *Alberta Building Code Barrier-Free Design Criteria*, the *Access Canada Optimal Accessibility Criteria,* and *Making Our Offices Universally Accessible: Guidelines for Physicians.* The calculated percentages state the compliance rate to the four accessibility audit tools.

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8	Site 9	Site 10
Barrier-Free Health and Medical Services Audit Tool	72%	74%	91%	60%	76%	86%	82%	77%	78%	83%
Number of Criteria Adhered to (Yes)	95	73	111	71	82	83	96	79	81	95
Number of Criteria Not Adhered to (No)	37	25	11	48	26	14	21	24	23	20
Number of Criteria Not Applicable	135	169	145	148	159	170	150	164	163	152
Alberta Building Code Barrier-Free Design Criteria Only	76%	76%	93%	61%	76%	92%	86%	78%	82%	84%
Number of Criteria Adhered to (Yes)	92	63	99	66	69	78	90	69	72	85
Number of Criteria Not Adhered to (No)	29	20	8	43	22	7	15	20	16	16
Number of Criteria Not Applicable	126	164	140	138	156	162	142	158	159	146
Access Canada Optimal Accessibility Criteria Only	50%	71%	67%	100%	88%	33%	67%	75%	75%	75%
Number of Criteria Adhered to (Yes)	1	5	4	2	7	1	2	6	6	6
Number of Criteria Not Adhered to (No)	1	2	2	0	1	2	1	2	2	2
Number of Criteria Not Applicable	9	4	5	9	3	8	8	3	3	3
Making Our Offices Universally Accessible: Guidelines for Physicians Only	22%	63%	89%	38%	67%	44%	44%	67%	38%	67%
Number of Criteria Adhered to (Yes)	2	5	8	3	6	4	4	4	3	4
Number of Criteria Not Adhered to (No)	7	3	1	5	3	5	5	2	5	2
Number of Criteria Not Applicable	0	1	0	1	0	0	0	3	1	3

Figure 110: Results from the accessibility audits conducted by ACCD.

The following section describes the details of each interview and audit.

Site 1: Community Health Center

Site Description

Site 1 was located in a low-income neighbourhood with a high concentration of substance abuse, homelessness, drugs, and prostitution. The demographic consists mainly of First Nations people, single unemployed males, and a large immigrant population. According to

the director, the majority of patients accessing health and medical services have disabilities such as Fetal Alcohol Spectrum Disorder, mental illness, or physical impairments.

This facility offers medical, dental, mental health services, and health advocacy. In addition, at this facility individuals can access laboratory, chiropractor, acupuncture and optometry services. There is a women's health clinic and community nursing station. This site also offers occupational health programs.

In addition to these programs, Site 1 runs a safe house for women and a program designed to help people with a history of homelessness comply with their medication treatment regimens.

Interview: What We Heard

Many that access health and medical services at Site 1 are substance abusers, individuals with mental health impairments, and individuals that are experiencing many forms of violence. In light of these actualities, Site 1 has policies concerning these issues, but they do not have policies related specifically to people with disabilities. The facility does offer staff members five days of paid professional development – which can include training regarding disabilities. Currently, there is a scent-free policy in place that applies to administrative and medical staff members, but there is a lack of enforcement when it comes to non-medical staff and patients.

Site 1 has no policy regarding alternate forms of communication for people with disabilities, but the manager did say that every attempt is made to remove communication barriers when circumstance arise. For example, doctors and nurses at the facility have had to use written messages to communicate with patients with disabilities, and, at the patient's request, conversations have been typed on a computer, as well.

There are also no policies for managing the transfer of people with disabilities. If a patient needed to be transferred from his or her wheelchair to an examination table, the patient would be moved by staff members, regardless of the level of training staff have. During the interview it was stated that the facility does not have the capacity to weigh individuals in wheelchairs/scooters.

The facility does not normally provide written instructions for managing care at home. The main reason is that most of the patients who access this facility are homeless, without support, and have a variety of mental and physical health issues; however, if a patient requested this information, he or she would be provided with it.

In terms of providing patients with a written list of all medications, the manager does not feel this practice is applicable to the facility. As mentioned above, the majority of the health center's patients are homeless, and they have a variety of mental and physical health issues.

Furthermore, many of the patients are not capable of keeping appointments or understanding their own health issues. And because most of the patients are poor and homeless, it is impossible to contact them by phone or by making a house call. To get around this problem, the health center has an outreach team both of whom make their presence in the community known. The outreach team will visit local bars, hotels, drop-in centers, parks, and well-known hangout spots to track down patients, encourage them to keep

appointments, ask if they are taking their medication, and, in general, keep up to date on their condition and whereabouts.

The facility manager identified the following major barriers to providing care to people with disabilities:

- Lack of resources. Mental health programs and supports for people with physical disabilities are under-resourced.
- Poverty makes it impossible for people to access quality health care. The health center's representative said that poverty was a symptom of other problems. In too many cases, the people that walk through the center's doors have fallen through the cracks of the health care system because of mental health issues. In the representative's words, "they become involved with prostitution to earn money, begin taking drugs to cope with earning money in this way, and then are forced to continue with prostitution to make money to feed their drug habit."[321]

It is believed that allocation of financial resources needs to be done more efficiently. Government needs to understand the needs of the low income population and manage resources according to needs and not budgets. In addition, the health care system in Alberta is not reflective of the need for equity, especially when it comes to the treatment of homeless and mentally ill Albertans who cannot access appropriate health and medical services.

Accessibility Audit

According to the *Barrier-Free Health and Medical Services Audit Tool*, site 1 was 72% in compliance to the accessibility standards that were being measured. This site was 76% compliant to the standards outlined by the Alberta Building Code.

	Site 1
Barrier-Free Health and Medical Services Audit Tool	72%
Number of Criteria Adhered to (Yes)	95
Number of Criteria Not Adhered to (No)	37
Number of Criteria Not Applicable	135
Alberta Building Code Barrier-Free Design Criteria	76%
Number of Criteria Adhered to (Yes)	92
Number of Criteria Not Adhered to (No)	29
Number of Criteria Not Applicable	126
Access Canada Optimal Accessibility Criteria	50%
Number of Criteria Adhered to (Yes)	1
Number of Criteria Not Adhered to (No)	1
Number of Criteria Not Applicable	9
Making Our Offices Universally Accessible: Guidelines for Physicians	22%
Number of Criteria Adhered to (Yes)	2
Number of Criteria Do Not Adhered to (No)	7
Number of Criteria Not Applicable	0

Figure 111: Site 1: Accessibility audit results

Some of the major non-compliances with the Alberta Building Code for Site 1 are lack of accessible parking stalls, failure to maintain the outside pavement surfaces, lack of directional or informational signage to services, narrow hallways that lead to examination rooms and administrative offices, and lack of colour contrast.

[321] This statement is verbatim.

The examination rooms at this site did not have adjustable-height examination tables, and there were no horizontal grab bars mounted on the wall behind the examination table to support those who are trying to get on it.

The public washrooms at site 1 did not adhere to the Alberta Building Code. The lavatories stand at a height of 895 mm, well above the maximum allowable height of 865 mm. The pipes underneath were not insulated which could lead to potential hazardous situations. In addition, the faucet handles were not of a lever type which is required by the Code. Although the public washrooms do have grab bars, they were not of a kind permitted by code, and they were mounted incorrectly.

Other noted infractions for site 1 were:

- The door had no sliding latch or operating mechanism;
- The coat hook was mounted more than 200 mm above the maximum allowable height;
- There was no accessible table or shelf for changing a baby.

Site 1 lacked appropriate accessibility for patients with disabilities. The on-site manager clearly noted that the facility needs upgrading, and the goal is to have funds allocated toward accessibility improvements during the next fiscal year.

Site 2: Community Health Centre

Site Description

Site 2 is located in a rural community. People of all ages use this service, but it is increasingly being used by a significant numbers of First Nations people and senior citizens.

This site offers the following services such as an adult day program, community care, Alberta Aids to Daily Living equipment, and nursing services such as wound care, dressing changes, medication assistance, and intravenous therapy. Patients are able to access palliative care, respite services, early childhood development, and mental health services at this location. In addition, patients at Site 2 are able to access the following:

- Dental Health,
- Environmental Health,
- Health Promotion / Health Education / Injury Prevention,
- Nutrition Services,
- Public Health Nursing,
- Pre Natal Education,
- Communicable Disease Control and Follow Up,
- Healthy Beginnings,
- Healthy Families Home Visitation Program,
- Sexual Health,
- Traffic Safety,
- Travel Health,
- Well Child and Immunization Clinics,
- Social Work services,

- Rehabilitation Services such as audiology, occupational therapy, physiotherapy (including cardiac rehabilitation), respiratory, and speech language pathology.

Interview: What We Heard

The manager of Site 2 stated that there is a scent-free policy in place, but was unaware of any communication tools, policies, or strategies for people with disabilities who have trouble communicating. Although the manager reported that the staff is trained on policies and procedures for managing patients with disabilities, ACCD was not able to receive a copy of the policies and procedures, as they are internal documents.

The manager pointed out that staff members do receive professional development opportunities, which sometimes include safe-lifting practices, and courses on communication strategies.

People with disabilities who access this facility are provided with written instructions for managing care at home. The extra time required to provide this service is relative to the individual case. In some instances, it can take an additional 10 to 15 minutes. In many instances, no extra time is required at all, since generic written instructions are available, they can be printed and provided to patients.

The manager's personal satisfaction with the community health centre rated as excellent, due to dedicated staff members who contribute to the patient-centred focus and vision of the community health centre.

The principal barrier to health and medical services, according to the manager, is funding. At the time of the interview, the manager was expecting cuts to respite services and preventative care. Another major barrier for patients is transportation. The region in which this facility is located is spread out over a large area, and patients have to travel significant distances in order to access services, which is often not possible.

The manager felt this problem could be remedied by allowing nurses to transport patients in their own vehicles to and from appointments. Unfortunately, there is no funding for the acquisition of proper insurance to allow nurses to drive patients when needed. The manager also felt nurses should have funding to make house calls to conduct minor health check tests.

Accessibility Audit

According to the accessibility audit conducted by ACCD, site 2 was 74% compliant to the *Barrier-Free Health and Medical Services Audit Tool*, and it was 76% compliant to the *Alberta Building Code Barrier-Free Design Criteria*.

	Site 2
Barrier-Free Health and Medical Services Entire Audit Tool	74%
Number of Criteria Adhered to (Yes)	73
Number of Criteria Not Adhered to (No)	25
Number of Criteria Not Applicable	169
Alberta Building Code Barrier-Free Design Criteria	76%
Number of Criteria Adhered to (Yes)	63
Number of Criteria Not Adhered to (No)	20
Number of Criteria Not Applicable	164
Access Canada Optimal Accessibility Criteria	71%
Number of Criteria Adhered to (Yes)	5
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	4
Making Our Offices Universally Accessible: Guidelines for Physicians	63%
Number of Criteria Adhered to (Yes)	5
Number of Criteria Not Adhered to (No)	3
Number of Criteria Not Applicable	1

Figure 112: Site 2: Accessibility audit results

The ACCD audit revealed few accessibility non-compliances with the parking area at Site 2. The surface signs indicating the universal symbol of accessibility were mostly worn away, and the width of accessible stalls was impossible to determine, since the lines that once marked them were no longer apparent.

In the Alberta Building Code, it is stated that any openings on the path of travel should not be greater than 13 mm in diameter. At site 2, the sphere openings that were aligned with the path of travel and permit the passage, measured greater than the Code requirements. In addition, at site 2 every door had a knob handle instead of a lever handle.

The audit revealed that there is a height-adjustable bed at site 2; however, none of the examinations tables had grab bars mounted on the walls behind them.

The doors to the public washrooms had knob handles. The door lock was also inaccessible, since it was a small push button that required strength and dexterity to operate. In addition, the toilet was mounted 30 mm above the maximum height allowance of 490 mm. There was a grab bar to help with transferring, but it did not have the proper knurled finish or dimensions.

Site 3: Geriatric Outpatient Clinic in a Hospital Setting

Site Description

Site 3 is located in an urban inner-city area. It provides in-depth geriatric diagnostic, assessment and treatment recommendations on an outpatient basis.

Interview: What We Heard

Site 3 has a scent-free policy which is strictly enforced. In terms of having tools, policies, or strategies for people with disabilities, the interviewed manager stated that staff members do not rely on strict policies. It is assumed that policies can be limiting because each patient's

needs are unique. Staff members assess the individual needs of each person that comes to the clinic.

The manager explained that they do have procedures in place for properly lifting and/or transferring patients. The purpose of these procedures is to prevent injuries to staff members and the patients with whom they work.

Training is offered to the support staff regarding how to work and assist people with disabilities. Yearly training is mandatory and related to the procedures followed in the clinic.

People with disabilities are given written instructions on managing care at home. The time it takes to do this it is not considered extra time but as a component of the assessment. If needed, patients are also given a written list of all medications.

The site manager sees transportation to the clinic as a major barrier to providing care to people with disabilities. Patients with disabilities have problems with accessing appropriate public transit and they are often unable to secure transportation from family members. Removing transportation barriers would help a lot more people access the services provided by the clinic.

Accessibility Audit

This geriatric outpatient clinic was 93% compliant to the *Alberta Building Code Barrier-Free Design Criteria.* This site measured a higher percentage of compliance when compared to other sites in terms of the Alberta Building Code requirements.

	Site 3
Barrier-Free Health and Medical Services Entire Audit Tool	91%
Number of Criteria Adhered to (Yes)	111
Number of Criteria Not Adhered to (No)	11
Number of Criteria Not Applicable	145
Alberta Building Code Barrier-Free Design Criteria	93%
Number of Criteria Adhered to (Yes)	99
Number of Criteria Not Adhered to (No)	8
Number of Criteria Not Applicable	140
Access Canada Optimal Accessibility Criteria	67%
Number of Criteria Adhered to (Yes)	4
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	5
Making Our Offices Universally Accessible: Guidelines for Physicians	89%
Number of Criteria Adhered to (Yes)	8
Number of Criteria Not Adhered to (No)	1
Number of Criteria Not Applicable	0

Figure 113: Site 3: Accessibility audit results

The parking lot and exterior paths of travel showed no barriers to accessibility according to the requirements. The number of accessible stalls is in excess of what is required, and the underground parkade in which they are located ensures that the surface is always free of snow and ice.

The only barrier noted in the waiting room was the lowered section of counter at the receptionist's desk. Although this section of counter space was wide enough and the right

height, the depth of space measured at 300 mm which is 185 mm short of the minimum allowable depth.

The examination rooms were accessible to people with disabilities. In addition to meeting all the requirements of the Alberta Building Code, these rooms each have an electronic height-adjustable table. The only barrier noted in the examination rooms was the lack of grab bars that need to be mounted on the walls behind examination tables.

The following are some of the improvements necessary for this clinic to be 100% compliant with the building code:

- Serif fonts are found on all of the signage in the clinic, which poses a barrier to people with visual disabilities. Also, there is no Braille incorporated into any of the signs.
- The door of the public washroom does not have a lock option that can be operated with a closed fist.
- The pipes below the lavatory are exposed, but the water temperature at this site is regulated, so there is no chance of people receiving a burn.
- The vanity was mounted at a height greater than 1000 mm which the maximum allowable under the Alberta Building Code.
- The coat hook in this washroom is mounted at a height of 1800 mm instead of 1400 mm.
- Where the washroom door swings towards the approach side, there was not adequate space for wheelchair users beyond the latch side of the door.

Site 4: Diagnostic Laboratory

Site Description

Site 4 is located in an older building in an urban setting that serves approximately sixty thousand residents.

Patients are able to access the following services:

- Biochemistry and Toxicology
- Urinalysis
- Transfusion medicine
- Hematology
- Coagulation studies
- Microbiology
- Serology
- Surgical pathology
- Cytopathology
- Autopsy pathology
- Morgue services
- Point of care services

The laboratory performs testing for screening, diagnosis, treatment, monitoring, and prevention of disease. In addition, the laboratory receives requests from physicians, dentists, nurse and infection control practioners, medical officer's of health, and pharmacists. It provides specimen collection, analysis of blood and body fluids and test results, and

interpretation to inpatient's, outpatients, emergency, community, ambulatory, cancer clinic and public health requests.

Interview: What We Heard

Site 4 has a scent-free policy that addresses the smell of staff members who are cigarette smokers.

Currently, site 4 does not have any particular communication tools, policies, or strategies for people who have difficulty communicating; however, the manager is aware that other facilities use pictograms to explain procedures to those who have difficulty communicating.

There are no policies or procedures for managing people with disabilities, but the manager emphasized that each staff member is aware of the need to accommodate those who require accommodation. For example, staff members do make house calls when patients cannot make it to site 4 for services such as blood work.

There is no specific policy for training support staff in how to work with and assist people with disabilities; however, such training would be provided upon request. The manager did say that staff members are trained in the provision of home care services. Depending on need, written instructions on managing home care are given to people with disabilities, but these instructions are only relevant to giving blood samples.

The manager of site 4 was very pleased with service provision at the laboratory and feels that the health care system needs only minor reforms. One change would be to empower home care nurses to be able to do point of care testing. The manager added that doctors do not need to be the "gatekeepers" – nurses, pharmacists, and other disciplines could work together better and make the system more efficient.

Accessibility Audit

According to the *Barrier-Free Health and Medical Services Audit Tool*, this site adhered to the criteria 60% and according to the *Alberta Building Code Barrier-Free Design Criteria* 61%.

	Site 4
Barrier-Free Health and Medical Services Entire Audit Tool	**60%**
Number of Criteria Adhered to (Yes)	71
Number of Criteria Not Adhered to (No)	48
Number of Criteria Not Applicable	148
Alberta Building Code Barrier-Free Design Criteria	**61%**
Number of Criteria Adhered to (Yes)	66
Number of Criteria Not Adhered to (No)	43
Number of Criteria Not Applicable	138
Access Canada Optimal Accessibility Criteria	**100%**
Number of Criteria Adhered to (Yes)	2
Number of Criteria Not Adhered to (No)	0
Number of Criteria Not Applicable	9
Making Our Offices Universally Accessible: Guidelines for Physicians	**38%**
Number of Criteria Adhered to (Yes)	3
Number of Criteria Not Adhered to (No)	5
Number of Criteria Not Applicable	1

Figure 114: Site 4: Accessibility audit results

The audit performed by ACCD revealed many non-compliance issues regarding accessibility at site 4. Some of the issues were:

- No clearly defined accessible parking stalls;
- Lack of directional and informational signage;
- Lack of handrails on the exterior stairs;
- Doors have knob handles;

In addition, the building has not been properly maintained in order to prevent imperfections to the outdoor surface.

The elevator's vintage predates barrier-free design. The lights and sounds to indicate where the elevator is in the hoist way were ineffective. The elevator buttons were imperceptible to people who are blind or those who have a visual disability. In addition, the size of the car is not suited to accommodate wheelchair users.

The examination rooms did not have adjustable examination tables and grab bars mounted behind the tables.

The ACCD audit revealed accessibility barriers at the washroom as well:

- Knob door handle;
- Faucets that are not lever type;
- The space underneath the lavatory measured less than the required 760 mm for width and 735 mm for height.
- The toilet was 390 mm which is 10 mm lower than the minimum required height.

Site 5: Diagnostic Imaging Facility

Site Description

Site 5 is located in a hospital that is in an urban setting. This site provides basic diagnostic imaging examinations, including MRIs, CT scans, X-rays, fluoroscopy, and mammograms.

Interview: What We Heard

According to the interviewed manager, site 5 has had a scent-free policy in place for more than ten years. Site 5's strategy for communicating with people with disabilities who have communication difficulties is to ensure that all potential barriers are disclosed at the time of the appointment. Once barriers are identified, staff members do their best to accommodate people with disabilities. According to the manager there have been no communication issues with people with disabilities.

The manager of site 5 stated that their policies and procedures for managing people with disabilities include training staff for manual and equipment-assisted lifting techniques. Since patients with dementia or brain injuries are often fearful or suspicious of laboratory exams, staff members are trained to manage these situations so that patients are as comfortable as possible with the services provided.

When needed, written instructions for managing home care are provided, but this takes no extra time. Instructions are printed off of the computer.

When enquired about the personal view on the current state of the health system, the manager of site 5 said that fundamental changes were needed. The manager recognizes the need for fiscal accountability, but feels that too often money is put before patients. The manager wants to see a system that is more patient focused and dedicated to helping people.

Training, communication materials, and allocated funding are the largest barriers existing in the health care system, according to the interviewed manager. The manager feels the current training is too general and that staff members would benefit from training that teaches staff members to manage specific disabilities. When it comes to communication materials, the manager said that Alberta Health Services should develop a cost-effective plan for production and distribution of communications in alternate formats, such as Braille.

The manager also cited the need for better access to acute care exams and diagnostic tests; accessible information, produced in a central location that can be adjusted according to need. Also, the manager suggested the development of a communication strategy outlining the need for better barrier-free policy and physical environments, one that is directed towards decision makers.

Accessibility Audit

Site 5 was 76% compliant to the *Barrier-Free Health and Medical Services Audit Tool*, and 76% compliant to the Alberta Building Code.

	Site 5
Barrier-Free Health and Medical Services Entire Audit Tool	76%
Number of Criteria Adhered to (Yes)	82
Number of Criteria Not Adhered to (No)	26
Number of Criteria Not Applicable	159
Alberta Building Code Barrier-Free Design Criteria	76%
Number of Criteria Adhered to (Yes)	69
Number of Criteria Not Adhered to (No)	22
Number of Criteria Not Applicable	156
Access Canada Optimal Accessibility Criteria	88%
Number of Criteria Adhered to (Yes)	7
Number of Criteria Do Not Adhered to (No)	1
Number of Criteria Not Applicable	3
Making Our Offices Universally Accessible: Guidelines for Physicians	67%
Number of Criteria Adhered to (Yes)	6
Number of Criteria Not Adhered to (No)	3
Number of Criteria Not Applicable	0

Figure 115: Site 5: Accessibility audit results

The audit revealed that this site had a parking area that complied with the accessibility requirements; however, it was noted that there was a lack of signage to inform visitors about accessible parking and path of travel. In addition, it was noted that many of the doors at this site measured the mandatory 600 mm of space beyond the latch side of the door where the door swings toward the approach.

Other areas that were not according to standards:

- Lack of necessary colour contrast.
- The mammogram room lacked the necessary 1500 mm turning radius and passage ways that are a minimum of 920 mm wide.
- Lack of grab bars in the examination rooms.
- No back support on the toilet in the washroom.
- Grab bars in the washroom not installed according to the Alberta Building Code requirements.
- The coat hook in the washroom is mounted 100 mm too high.

It was noted that the examination rooms at this site were equipped with height-adjustable tables.

Site 6: Gynaecologist and Obstetrician Clinic

Site Description

Site 6 is located in an urban setting. The services offered in this office are used by women only.

Interview: What We Heard

The interviewed manager informed that there is a scent-free policy at this site. There are no communication tools, policies, or strategies in place for managing patients with disabilities, but the manager stated that accommodations would be made if a situation were to arise.

According to the manager, there have been no requests about training opportunities for support staff who want to learn how to work with and assist people with disabilities. The manager would not reveal if such training would be provided upon request.

It was stated that the patients who access health services at site 6 have never requested written instructions for managing home care, and staff members rely on pharmacies to provide people with written lists of medications.

The manager said the prevalent barrier in site 6 is the lack of ability to accommodate women with severe physical disabilities who have to be referred to a nearby hospital for gynaecological and obstetrician services.

When asked for solutions to improve access to the health care system, the manager pointed out that accessibility is not an issue; however, things might change in the future.

Accessibility Audit

The gynaecological and obstetrician clinic was 86% compliant to the accessibility requirements in the *Barrier-Free Health and Medical Services Audit Tool,* and 92% compliant to the Alberta Building Code. The chart below shows the accessibility of site 6 in accordance to the various measurement tools.

	Site 6
Barrier-Free Health and Medical Services Entire Audit Tool	86%
Number of Criteria Adhered to (Yes)	83
Number of Criteria Not Adhered to (No)	14
Number of Criteria Not Applicable	170
Alberta Building Code Barrier-Free Design Criteria	92%
Number of Criteria Adhered to (Yes)	78
Number of Criteria Not Adhered to (No)	7
Number of Criteria Not Applicable	162
Access Canada Optimal Accessibility Criteria	33%
Number of Criteria Adhered to (Yes)	1
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	8
Making Our Offices Universally Accessible: Guidelines for Physicians	44%
Number of Criteria Adhered to (Yes)	4
Number of Criteria Not Adhered to (No)	5
Number of Criteria Not Applicable	0

Figure 116: Site 6: Accessibility audit results

The parking area at this clinic meets the requirements of the Alberta Building Code and the *ACCD Barrier-Free Health and Medical Services Audit Tool*.

It was noted that the clinic lacks directional and informational signage, and there was no space in the waiting room to accommodate wheelchair/scooter users. Examination rooms were not equipped with height-adjustable tables, and there were no grab bars installed to assist patients.

The public washroom was not according to the Alberta Building Code requirements. The soap, towel dispensers and the coat hook were mounted higher than the 1200 mm maximum allowable height, and there were no signs to identify the public washroom as accessible.

Site 7: Community Health Clinic

Site Description

Site 7 is a community health clinic located in an urban area on a college campus. Access to sexual health, mental health, STD tracing, body image, immunization, and lactation consultant services are available at site 7. In addition, laboratory and x-ray services are available on site. This clinic has ten patient rooms, one lab, one X-ray, and a procedure room. Site 7 is a primary health care clinic where patients have the option to make appointments or walk-in.

Interview: What we Heard

There is a scent policy which is strictly enforced, in part because there is a staff member who is scent sensitive. This site does not exclusively have communication tools, policies, or strategies for people with disabilities who have difficulty communicating.

The director of this facility stated that they do have policies for managing patients with disabilities, but could not recall any situations where there have been issues about providing services to patients with disabilities. It was mentioned that if an issue came up, the policies and procedures would then be accessed and implemented. In addition, written instructions

regarding managing care at home are given to those who need them. Patients are not routinely given a written list of all medications.

Training is offered to support staff in how to assist people with disabilities. Staff members were recently trained in crisis intervention and how to assist patients with brain injuries.

When asked to rate personal satisfaction with the community health centre, the director said it was poor. The physicians are chronically late for work, and they often leave early, making things incredibly frustrating for patients and other staff members.

When asked for an opinion on the state of Alberta's health care system, the director said it only required minor changes, that things are generally headed in the right direction, and that streamlining services is the way to go.

The following were listed as the major barriers to providing care to people with disabilities:

- Lack of knowledge and resources;
- People's unwillingness to disclose hidden disabilities; and,
- Transportation

When asked what could be improved immediately, the director said that training for management and staff needed immediate improvement. This training should focus on communication and background knowledge.

Accessibility Audit

Site 7 exhibited higher compliance with the Alberta Building Code requirements than the requirements of the *Barrier-Free Health and Medical Services Audit Tool*. The chart below shows the compliances to the four different measurement tools.

	Site 7
Barrier-Free Health and Medical Services Entire Audit Tool	82%
Number of Criteria Adhered to (Yes)	96
Number of Criteria Not Adhered to (No)	21
Number of Criteria Not Applicable	150
Alberta Building Code Barrier-Free Design Criteria	86%
Number of Criteria Adhered to (Yes)	90
Number of Criteria Not Adhered to (No)	15
Number of Criteria Not Applicable	142
Access Canada Optimal Accessibility Criteria	67%
Number of Criteria Adhered to (Yes)	2
Number of Criteria Not Adhered to (No)	1
Number of Criteria Not Applicable	8
Making Our Offices Universally Accessible: Guidelines for Physicians	44%
Number of Criteria Adhered to (Yes)	4
Number of Criteria Not Adhered to (No)	5
Number of Criteria Not Applicable	0

Figure 117: Site 7: Accessibility audit results

The parking lot at this facility had clearly marked parking stalls for people with disabilities and a path of travel to the front door that was free of any barriers; however, the site lacks signage to inform patients about accessible entrances. The front steps did not have tactile strips to indicate change in elevation.

The public washroom at site 7 had accessibility issues such as:

- The front edge of the counter measured a height of 650 mm, which is lower than the 856 mm required according to the Alberta Building Code.
- The toilet stands at 390 mm. The Alberta Building Code allows toilets to stand at a height between 400 mm and 460 mm above the finished floor surface. Any height outside of this range is considered inaccessible.
- The mirror is mounted at 1230 mm above the floor while the requirement is for the mirror not to be mounted more than 1000 mm above the floor.

The ACCD audit revealed that the examination rooms are not equipped with adjustable tables, or horizontal grab bars mounted on the wall behind the tables, or fixed or portable lift systems, or scales for weighing patients who use wheelchairs.

Sites 8, 9 and 10: Diagnostic Laboratory Services

Sites Description

Sites 8, 9, and 10 are part of a corporate chain of diagnostic laboratories. They are located in an urban setting.

Interview: What we Heard

All three laboratories are guided by the same policies and procedures. The laboratories have a scent-free policy that is strictly enforced. The scent-free policy was part of the environmental policies in place for the laboratory setting.

This corporate chain does not have communication tools, policies, or strategies for people with disabilities who have difficulty communicating. They do provide translation services to overcome language barriers. In addition, there are policies regarding service dogs and dogs in training, which are allowed at all laboratory locations.

There are no specific procedures or policies for assisting people with disabilities who are trying to access services. Staff members are provided with limited details about the patient history and each situation is considered on individual merits. If unusual circumstances arise, management is contacted which guides the decision-making process.

The laboratories are guided by procedures for immobilizing patients who have involuntary movement or whose anxiety might cause them to move suddenly thus creating a hazard for staff members. There are also policies for positioning patients so that they are comfortable and safe. This involves a discussion directly with the patient or with the patient's caregiver.

Training and support for assisting people with disabilities is not specifically provided. Management offers professional development seminars once a year, but the content usually deals with emerging issues which are determined in advance.

Patients are given written instructions for providing samples at home and for preparing for collection; however, these instructions are not provided in alternate formats for people who are blind or those with visual impairments.

The interviewed manager revealed that the most recent internal environmental scan revealed gaps in accessibility for people with disabilities. It was noted that many of the policies are broad and do not deal directly with specific issues.

The manager was confident about the care plans they provide to people with disabilities. This involves a dialogue with patients with disabilities in determining the most suitable collection sites and necessary accommodations.

Concerning the current state of the health system in Alberta, the interviewed manager stated that the emerging gaps suggest that changes are desirable; however, the optimism of anything improving immediately was minimal.

The following improvements to accessibility were recommended by the manager:

- Standardized accessibility features at every facility
- Better information and communications strategies for engaging people with disabilities.

The following sections will describe the findings from the accessibility audits conducted at sites 8, 9 and 10.

Site 8: Diagnostic Laboratory Services

Accessibility Audit

Site 8 exhibited higher compliance with the Alberta Building Code than the *Barrier-Free Health and Medical Services Audit Tool*. The chart below shows the compliances to the four different measurement tools.

	Site 8
Barrier-Free Health and Medical Services Audit Tool	77%
Number of Criteria Adhered to (Yes)	79
Number of Criteria Not Adhered to (No)	24
Number of Criteria Not Applicable	164
Alberta Building Code Barrier-Free Design Criteria Only	78%
Number of Criteria Adhered to (Yes)	69
Number of Criteria Not Adhered to (No)	20
Number of Criteria Not Applicable	158
Access Canada Optimal Accessibility Criteria Only	75%
Number of Criteria Adhered to (Yes)	6
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	3
Making Our Offices Universally Accessible: Guidelines for Physicians Only	67%
Number of Criteria Adhered to (Yes)	4
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	3

Figure 118: Site 8: Accessibility audit results

The parking lot at this site was not in compliance with the requirements of the Alberta Building Code. There were no clearly marked accessible parking stalls or directional signage. Individuals with disabilities will have to walk approximately 50 yards to the east side of the building, in order to access a curb cut. In addition, the pavement has heaved and caused the door's threshold to be raised more than the 13 mm allowed by the Alberta Building Code.

The universal washroom showed few accessibility issues during the audit:

- The washroom door had a push-button lock – a style of lock which is not easily operable by individuals with limited dexterity.
- The lavatory does not provide enough room between the side wall and the centre of the sink. Currently there is 400 mm of free space rather than the 460 mm required.
- The front edge of the washroom counter measured 730 mm high rather than the minimum allowable height of 735 mm.
- The pipes below the lavatory pose a barrier to wheelchair users who can still fit under the lavatory, despite its non-compliant dimensions. The metal pipes had no insulation.
- The overall dimensions of the universal toilet room were also non-compliant with the Alberta Building Code. The code requires that universal toilet rooms have dimension no less than 1700 mm. The washroom at Site 8 measured at 1500 mm.
- The universal washroom's coat hook was mounted too high and protruded too far. Instead of being mounted at a height of 1400 mm and protruding no more than 50 mm, the coat hook in this washroom was mounted at 1600 mm and protruded 90 mm.

The waiting room exhibited accessibility barriers as well. There were no open spaces for patients who are wheelchairs/scooters users. The counter at reception had a lowered section; however, there was no recessed space below it to accommodate wheelchair/scooter users. The requirement is for the space below the counter to be 760 mm wide, 685 mm high, and 485 mm deep.

In the patient rooms, there were no grab bars on the walls to assist individuals with disabilities during tests.

Site 9: Diagnostic Laboratory Services

Accessibility Audit

Site 9 exhibited higher compliance with the Alberta Building Code rather than the *Barrier-Free Health and Medical Services Audit Tool*. This site rated only 38% in compliance with the recommendations from the *Making Our Offices Universally Accessible: Guidelines for Physicians*. The chart below shows the compliances for site 9 to the four different measurement tools.

	Site 9
Barrier-Free Health and Medical Services Audit Tool	78%
Number of Criteria Adhered to (Yes)	81
Number of Criteria Not Adhered to (No)	23
Number of Criteria Not Applicable	163
Alberta Building Code Barrier-Free Design Criteria Only	82%
Number of Criteria Adhered to (Yes)	72
Number of Criteria Not Adhered to (No)	16
Number of Criteria Not Applicable	159
Access Canada Optimal Accessibility Criteria Only	75%
Number of Criteria Adhered to (Yes)	6
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	3
Making Our Offices Universally Accessible: Guidelines for Physicians Only	38%
Number of Criteria Adhered to (Yes)	3
Number of Criteria Not Adhered to (No)	5
Number of Criteria Not Applicable	1

Figure 119: Site 9: Accessibility audit results

The parking area at site 9 met the requirements of the Alberta Building Code; however, there were no directional and informational signs to indicate the presence of a barrier-free entrance.

The following non-compliances were noted regarding the universal washroom:

- There was a button lock rather than a sliding latch on the door.
- The pipes underneath the lavatory were exposed.
- The coat hook was mounted 100 mm too high than the requirements.
- No folding table for changing babies.

The waiting room doors have knobs rather than lever. In addition, there were no spaces in the waiting room to accommodate wheelchairs/scooter users. Also, there was no lowered section at the receptionist's counter.

The examination table used for patients to lie down on during blood tests was not height-adjustable, and there were no grab bars on the wall.

There was a lack of directional and informational signage for individuals with visual impairments.

Site 10: Diagnostic Laboratory Services

Accessibility Audit

Site 10 exhibited the highest compliance rate compared to site 8 and site 9. The chart below shows the compliances to the four different measurement tools.

	Site 10
Barrier-Free Health and Medical Services Audit Tool	83%
Number of Criteria Adhered to (Yes)	95
Number of Criteria Not Adhered to (No)	20
Number of Criteria Not Applicable	152
Alberta Building Code Barrier-Free Design Criteria Only	84%
Number of Criteria Adhered to (Yes)	85
Number of Criteria Not Adhered to (No)	16
Number of Criteria Not Applicable	146
Access Canada Optimal Accessibility Criteria Only	75%
Number of Criteria Adhered to (Yes)	6
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	3
Making Our Offices Universally Accessible: Guidelines for Physicians Only	67%
Number of Criteria Adhered to (Yes)	4
Number of Criteria Not Adhered to (No)	2
Number of Criteria Not Applicable	3

Figure 120: Site 10: Accessibility audit results

At site 10, the parking stalls for people with disabilities were not clearly marked, and there were no clearly defined accessible stalls. Also, there was no directional and informational signage to lead patients to accessible entrances.

This clinic had a set of interior stairs. With the exception of handrails that did not extend for 300 mm beyond the last riser, these stairs were compliant with the barrier-free section of the building code.

The following barriers were noted in the universal washroom:

- No sliding latch on the door.
- At the lavatory, the distance between the side wall and the centre of the sink is 380 mm, when it should be 460 mm.
- For people who use wheelchairs, fitting under the front edge of the lavatory counter would be difficult. The front edge, which measures 725 mm above the finished floor surface, is 10 mm short of the minimum allowable height, 735 mm. At a distance 205 mm back from the front edge, the height is also insufficient, measuring less than the minimum allowable height of 685 mm.
- The grab bars at the washroom were mounted incorrectly.
- The coat hook was mounted at a height greater than 1400 mm.
- There is no folding table for changing babies.

The receptionist's counter did not have a lowered section, and there was no available space for patients who are wheelchair/scooter users. Also, in the patient rooms there were no horizontal grab bars mounted on the walls.

Conclusion

The ACCD accessibility audits revealed that there are numerous barriers to health and medical services in Alberta. Individuals are prevented from entering medical offices because of inaccessibility and lack of adherence to the Alberta Building Code.

The site audits revealed that site managers are aware of the various barriers; however, limited funding allocations and established policies lead to processes and procedures that are limiting to many patients with disabilities. In addition, there was an evident lack of written policies and procedures about provision of care to patients with disabilities.

Barrier-Free Health and Medical Services in Alberta Project: Recommendations

ACCD's *Barrier-Free Health and Medical Services in Alberta* project was an initiative to identify barriers to health and medical services perceived and experienced by Albertans with disabilities when accessing preventative and ongoing health services.

From April to July 2010, ACCD conducted a multi-part needs assessment of the barriers that people with disabilities experience when accessing health and medical services in Alberta. Given that a review of the literature indicated the importance of creating health care that is responsive to the needs of all citizens; it was considered essential to solicit input from people with disabilities, not-for-profit organizations, and health care professionals. A balance of urban and rural discussion was sought in the consultations.

Despite this diversity, each phase of the needs assessment reported common themes. Most notably, all phases reported that there are barriers in the health care system – barriers that are being created as a response to current policymaking without seeking input from patients and health care professionals. Participants overwhelmingly reported the need for a diverse range of services and for the government to assist health care professionals in providing these services in an appropriate and timely manner. Every consulted location has been significantly affected by current government restructuring of services and lack of funding opportunities.

The results of the *ACCD Barrier-Free Health and Medical Services in Alberta* project cannot be summed up in a single overarching recommendation for creating barrier free health and medical services. The literature review, the community consultations, and the questionnaires filled out by people with disabilities and health care professionals portrayed a picture of complexity – a health services delivery system that depends on budgets, human resources, and meeting the needs of the population it serves. The challenge is how to establish a proficient health care system and meet the funding requirements that will follow.

This section outlines the recommendations that were developed as a result of the findings from the ACCD *Barrier-Free Health and Medical Services in Alberta* project. The recommendations are categorized under two headings:

- System-wide improvement recommendations
- Disability-specific recommendations

System-Wide Improvement Recommendations

The following recommendations were developed to enhance Alberta's health care service delivery system:

Disability Awareness and Education

Disability awareness and education is crucial for establishing a foundation for barrier-free health and medical services in Alberta. Comments received from participants at the

community consultations and from the online questionnaires stated that lack of knowledge about disabilities acts as a roadblock to accessing health and medical services.

The following recommendations will contribute toward higher disability awareness:

- Develop effective strategies to raise awareness about the health care needs of people with disabilities.
- Create a program that will distinguish health care professionals who excel beyond their duties to assist patients with disabilities.
- Establish a patient-centred system where the patient will be considered a part of the decision-making team.

Service Delivery

Project participants stated that it is vital for services to be delivered when needed rather than after long-waiting periods.

The following recommendations will contribute toward establishing an efficient service delivery system:

- Establish an effective compensation system that will allow health care professionals to assist people with disabilities in a suitable and timely manner.
- Establish protocols and resources for health care professionals to develop written reports when considered essential for diagnosis and treatment of patients with disabilities.
- Appointments should be according to patient need (shorter for prescription renewal and longer for more complex needs).
- Allow, in extreme cases, home visitations by health care professionals.
- Create incentives to allow health professionals to develop care manuals.
- Create a tool that will allow disability knowledge sharing among health care professionals, such as establishing an electronic knowledge database.
- Provide incentives to recruit more specialists (e.g. autism spectrum disorders) in adult services.
- Develop a system that is proactive and focused on preventative services.

Rural health care Service Delivery

Patients with disabilities in rural areas are not able to access timely services because of an insufficient number of doctors and specialists providing services.

The following are proposed recommendations for improvement in rural health service delivery:

- Establish infrastructure for health services in rural areas so people can access services in their communities.
- Allocate resources for services in rural areas to perform day surgeries which will reduce waiting times and people will be able to receive timely and appropriate services in their own communities.

- Set up more frequent specialized traveling clinics for diagnostic tests.
- Eliminate the pay scale difference between urban and rural doctors.
- Create a plan of how to contract more health professionals to move to rural areas and remain long term.
- Establish medical teams with various specialists in every community.

Transition to services

At each consultation and in many survey responses, an issue that was commonly cited was the lack of transition from child to adult services. Once children turn 18, the support system is no longer effective or efficient.

Extensive transition planning has to be conducted to achieve the following:

- Ease the transition from children's health services to adult's health services.
- The transition of services between age 16 to 65 to 65 and over should be connected and seamless for the individual in the system.

Collaborations

ACCD project participants stated that there is a disconnect between various ministries and health departments in Alberta. Participants said they have to navigate through a system that does not include the opinion of the patient. The following collaborations are crucial:

- Establish collaborative initiatives between health professionals, Alberta Health Services, and Alberta Health and Wellness.
- Establish doctor-patient collaborative initiatives.

Decision making

There is a perception that patients are never consulted when changes are being considered and/or implemented.

The findings from the ACCD *Barrier-Free Health and Medical Services in Alberta* project indicate a need for the following:

- Patients with disabilities to be an integral part of the decision-making medical team.
- Decision-makers must understand the diversity of each community in Alberta. Many locations such as Lethbridge and Grande Prairie are still considered rural when services are allocated.

Information and referral

Significant frustration comes from the inability of patients to find appropriate and necessary information. Patients are being sent from one point of entry to another without success. It is crucial for the government to do the following:

- Establish a coordinated information system that will guide patients and their families toward appropriate and timely services. Even though there are various initiatives, such as the Health Link Information Line, many patients are unaware of these information and referral systems.
- Community organizations can act as information and referral resources.

Accessible offices and equipment

Accessibility is essential not only for patients with disabilities, but also for seniors and parents with children. Decision makers must establish polices that will maintain and encourage the following recommendations:

- New health care facilities should comply with and go beyond the Alberta Building Code.
- Develop standards that will guide health and medical professionals when establishing accessible offices.
- Provide incentives for health care professionals to establish practices in accessible offices.
- Mandate a minimum number of accessible exam rooms per number of patients or health care professionals.
- Mandate at least one fully accessible facility where people with disabilities can go to receive appropriate and adequate medical care.
- Update medical equipment to reflect the needs of the population. When developing policies regarding medical equipment, there should be consideration given to universally usable equipment. Equipment should be used by the maximum number of people.

Patient Education

According to the survey participants, many of the issues arise from patients with disabilities not having proper education about preventative and ongoing health care services and procedures. Establishing educational campaigns for patients with disabilities to learn about their responsibilities and the services available would assist them to become active participants in their health care needs. These educational campaigns could be successfully administered and delivered by community organizations that already assist people with disabilities to understand the health care system.

Disability-Specific Recommendations

The following recommendations address the particular challenges that are experienced by people with various impairments.

Hearing Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with hearing impairments.

- Establish protocols and standards for American Sign Language interpreting services when accessing health and medical services in Alberta.
- Provide education and awareness about the communication needs of individuals who are hard of hearing or deaf.
- Provide incentives for training and usage of communication technology.

Seeing Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with seeing impairments.
- Establish standards and requirements for better signage in health care facilities.
- Provide health care information in alternative forms of communication.

Speech Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with speech impairments.
- Allow health care professionals to allocate extra appointment times for individuals with speech impairments as proper communication is imperative for diagnosis and treatment.

Pain Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with pain impairments.
- Establish a system that will address the need for shorter waiting times.
- Implement and practice an holistic approach to illness management.
- Improve patient-doctor communication.

Learning Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with learning impairments.
- Establish communication resources between patients with learning impairments and health care professionals.

Mobility and Agility Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with mobility and agility impairments.
- Enhance collaborations between general practitioners and specialists when treating patients with mobility and agility impairments.
- Mandate development of accessible health care clinics and facilities, and the purchase of accessible medical equipment.
- Focus on preventative care.

Memory Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with memory impairments.
- Enhance the follow up system for patients with memory impairments.

Developmental Impairment: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with developmental impairments.
- Establish efficient access to patient information.
- Recruit specialists who can treat adults with Autistic Spectrum Disorders and other developmental impairments.

Psychological (mental) Impairments: Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with psychological (mental) impairments.
- Create a system that will focus on appropriate and timely mental health services.
- Provide services with respect and dignity.
- Establish appropriate communication methods with individuals with psychological (mental) impairments.
- Provide patient education and appropriate information and referral services.
- Create awareness about the side effects of diagnosis and treatment.

Multiple Impairments Related Service-Delivery Recommendations

- Provide disability awareness programs about the specific needs of individuals with multiple impairments.
- Allocate extra appointment times for multiple diagnosis and treatments.
- Train health care professionals about multiple diagnosis patients.
- Use an holistic approach to care.
- Develop efficient access to new treatments and therapies.

Conclusion

As Patricia Benner writes, "our moral sensibilities and possibilities in relation to our lifesaving technologies will require more than the objectified clinical vocabularies and clinical language that we presently use. Perhaps such development cannot be accomplished without some public space for weeping and for considering illness and death as human passages and not just clinical courses of disease."[322]

ACCD's position in the disability community, and its ability to engage health care professionals and government underlie the successful completion of each phase of this

[322] Benner, P. (2004). Seeing the Person beyond the Disease. *American Journal of Critical Care January 2004, Volume 13, No* . Retrieved on March 8, 2010, from http://ajcc.aacnjournals.org/cgi/reprint/13/1/75

project. The recommendations offered would not have been possible without collaboration from people with disabilities, community agencies, health care professionals, and government decision-makers.

The recommendations are based on the findings from the *ACCD Barrier-Free Health and Medical Services in Alberta* project. We strongly believe that evidence-based solutions can create a system where all patients can receive proper medical care. "Evidence-based decision-making as the 'foundation for an effective and efficient health system' has been endorsed by a number of Canadian Health Organizations including Health Canada and the Canadian Health Services Research Foundation."[323]

ACCD acknowledges the complexity of the issues and that many of the solutions require financial investment; however, implementing these recommendations will create cost-effective strategies by reducing the number of individuals with disabilities accessing long-term care facilities.

Albertans with disabilities are passionate about health care issues, and they contributed to the development of the recommendations for barrier-free health and medical services in Alberta. Moving forward, the intent of the project will be to assist decision-makers to produce policies that will have the greatest impact on the lives of people with disabilities.

[323] Armitage, G. et al. (2009). *Health Systems Integration: State of the Evidence*. *International Journal of Integrated Care – Vol. 9, 17 June 2009*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707589/pdf/ijic2009-200982.pdf

Appendix I: Community Consultations Summaries

Edmonton Community Consultation: A Summary of the Discussion (May 20, 2010)

Opening Remarks

Bev Matthiessen, Executive Director, and Melita Avdagovska, Research and Projects Coordinator, from the Alberta Committee of Citizens with Disabilities welcomed the participants and thanked them for coming today to be part of this very important initiative. Bev opened the consultation with an historical perspective of ACCD and the work that is presently being done. She explained that ACCD has received numerous complaints through the years about access issues people with disabilities have to health and medical services. That is why ACCD became involved in this project.

Melita explained that ACCD's *Barrier-Free Health and Medical Services in Alberta* project is an initiative to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health services. The *Barrier-Free Health and Medical Services in Alberta* project has two phases. During the first phase, ACCD will be conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Questionnaires have been distributed to people with disabilities and health professionals, and there will be six community consultations at various locations throughout the province. The information collected from the literature review, the questionnaires, and the community consultations will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health, and medical services for people with disabilities. In the second phase, ACCD will develop a communications plan and media campaign for disseminating our findings and recommendations to medical professionals, the disability community, and the general public.

Melita began the session by asking participants to introduce themselves by completing the following sentence:

> ***The reason I attended this community consultation is…***

The responses were:

- I have seen many barriers to health services and experienced many of them myself personally.
- I struggle with accessibility and communication.
- There are too many issues for people with spinal cord injury when it comes to health care services.
- I have MS and my tolerance with barriers is gone. There is a constant struggle for me.
- To learn how the rest of the community is coping.
- To raise awareness about the Deaf Blind community and the barriers faced.
- To present issues about the struggle that people with autism have from childhood to adulthood.
- I would like to know how to navigate the system and find services.

- How caregivers can be assisted in their valuable role.
- Time for a change within the medical system.
- I am here to learn from other individuals who are helping others access health and medical services.
- What can be done about the deterioration of the system?
- I am not able to receive any help.
- Without barrier-free health services, people with disabilities cannot keep jobs.
- Healthcare access is limited when you have chemical sensitivity.
- The medical system has become too dependant on the pharmaceutical industry.
- There is no recognition for invisible disabilities.
- I need to receive better education and awareness about various services. It seems that I am falling through the cracks of the system.

Barriers to Accessing Health and Medical Services

Next, participants broke into small groups to discuss barriers when accessing health and medical services, with someone in each group chosen to act as a facilitator. Each member of the group was asked to list the significant barriers that he or she has experienced. Participants were asked to explain the process of how they experience barriers rather than give broad general statements. The barriers were categorized and written on post-it notes.

The post-it notes from each small discussion group were gathered and clustered by themes on flip-chart sheets.

The barriers by theme were:

- **The inappropriateness of the medical system and health professionals**
    - Waiting time for a specialist and to find out that no help can be offered.
    - Physically inaccessible offices.
    - Inaccessible exam rooms.
    - Labelled as a difficult or uncooperative patient.
    - New doctors prescribing ineffective therapies.
    - Lack of education and awareness regarding disabilities: symptoms, treatment, and disease.
    - Single symptom system.
    - Assistance only for those that 'fit in the box'.
    - Lack of patience.
    - Lack of basic medical equipment.
    - Over/under diagnosis due to lack of standardization.
    - Inefficiently connected medical system: inability to navigate through services.
    - Lack of appropriate physician/patient communication.
    - Lack of appropriate communication regarding side effects.
    - One appointment – one symptom.
    - Inappropriate access to emergency services.
    - Lack of scent-free environments.
    - Lack of acceptance for accompanying family members or care attendants.
    - Physicians are influenced by pharmaceutical companies.
    - Inappropriate referrals to avoid dealing with the problem.
    - Lack of disability clinics.

- More supports in Ontario than in Alberta.
- Inappropriate lighting in the rooms.
- Lack of appropriate signage.

- **Assistive technology and medical equipment**
  - Lack of funding for new communication devices.
  - Inappropriate AADL funding criteria.
  - Lack of education and awareness of necessary medical equipment.
  - Lack of alternative communication materials.
  - Lack of interpreters.
  - Inappropriate exam tables and medical equipment.

- **Communication barriers**
  - Interpreters are not trained to work with individuals who are deaf and have developmental disabilities.
  - How to encourage independence when that will require intrusion.
  - Physicians do not have patience to work with Deaf individuals.
  - Non-inclusion of the patient as part of the team.

- **System navigation**
  - Disconnect between service provider agencies and the government.
  - How to navigate a system that is not understood even by the individuals who work in it.

- **Government**
  - Provincial disparity between cities and rural programs.
  - Disparity among provinces.
  - Lack of appropriate information to guide you through the system.
  - Lack of appropriate knowledge of various funding programs.
  - Non-existent transition process from children services to adult services.
  - As soon as an individual leaves the school system, supports disappear.
  - No provincial employment strategies for people with disabilities.
  - Inconsistent transportation for doctor appointments.
  - Home care limitations.
  - More disabilities means programs and services are harder to find.
  - No abuse prevention programs that lead to life-long health issues.
  - Lack of training programs.

- **Caregiver**
  - No appropriate respite care programs.
  - Lack of respect and recognition.
  - Lack of staff recognition for the caregivers that come with the patients to appointments.

From Barriers to Solutions

Each of the themes was stated at the top of flip-chart sheets. Each flip-chart sheet had the post-it-notes on it that stated the barriers identified by the participants. The participant groups were asked to go to each flip chart sheet and discuss possible solutions to address the

barriers on post-it notes. When members had reached agreement, they wrote their suggestions on the flip-chart sheet. They moved to the next flip-chart sheet to consider the ideas left by the previous group and added any further solutions.

- **The inappropriateness of the medical system and health professionals**
  - Health professionals should participate in mandatory education and awareness training programs.
  - Health professionals should work with patient advocates to assist patients and their needs.
  - More rigorous oversight of how health professionals prescribe pharmaceuticals.
  - Implement the Alberta Building Code and create barrier-free facilities.
  - Portable patient lifts to be available at various locations.
  - Reimbursement system that will allow health professionals to assist people with disabilities in an appropriate and timely manner.
  - Disability navigators – the life span model.
  - Enhance capacity building.
  - Directed PCN's.
  - Purchase accessible medical equipment to perform various exams.
  - Height-adjustable medical exam tables.

- **Assistive technology and medical equipment**
  - Set up video phones/TTY in public places.
  - Clinics should have at least one height-adjustable exam table.
  - There should be patient lift equipment in more locations.
  - Braille on signs.

- **Communication barriers**
  - Electronic record so conditions do not need to be re-explained.
  - Innovative reimbursement system to allow patients with disabilities the appointment time they need when accessing health and medical services.
  - The patient needs to be made part of the medical team.
  - Staff education and awareness regarding various disabilities.
  - Respectful attitudes by medical professionals.
  - Funding for interpreters and interveners.
  - Communication assistance.
  - Guardians/support staff/caregivers should be included in the decision making process.

- **System navigation**
  - Coordinated information systems.
  - Support groups organized by medical facilities and specialist offices.
  - Create a patient database that is connected so people can network.

- **Government**
  - Need for a change with the AISH regulations.
  - Financial support for networking groups.
  - Establish an electronic knowledge database.
  - Establish education and awareness training funding.

- Create a solid system navigation process.
- Change to the health care rules and regulations.

Other issues

Participants raised the following additional barriers:

- **Housing shortage**
  - Housing that is not accessible.
  - There is a lack of accessible, safe, and affordable housing.
  - Low interest funds for renovations and modifications.
  - Enforce the building code.
  - Age appropriate housing options.
  - Supportive living options.

- **Inappropriate home care**
  - Insufficient amount of assistance.
  - Lack of care attendants.
  - Long assessments.

- **Caregiver**
  - Create an awareness campaign.
  - Individual capacity building.
  - Supportive services.
  - Enhance community resources.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. The following examples were given:

- Dr. Doug Klein at the Royal Alex Family Clinic
- Dr. Qaiser Raza Rizvi at the Plaza 66 Medicentre
- Dr. Mabel Luscombe at the Red Deer Hospital
- Dr. Mark Blais (Psychiatrist)
- Dr. Blaine Sanderman (pain specialist)
- Dr. Ken Makus (neurologist)
- Dr. Stephen Genuis (environmental specialist)
- Dr. John Guthrie at the Glenrose Hospital
- Autism Society of Edmonton Area
- Allin Medical Clinic in Edmonton
- Dr. Robert Pokroy (neurologist)
- Lynn Whitman (MS Specialist Nurse)
- Multiple Sclerosis Society of Alberta
- Down Syndrome Clinic

Wrap Up

Attendees were thanked for their participation and asked to contact ACCD if they had any further questions or comments.

Calgary Community Consultation: A Summary of the Discussion (May 31, 2010)

Opening Remarks

Bev Matthiessen, Executive Director, and Melita Avdagovska, Research and Projects Coordinator, from the Alberta Committee of Citizens with Disabilities welcomed the participants and thanked them for coming to be part of this very important initiative. Bev opened the consultation with an historical perspective of ACCD and the work that is presently being done. She explained that ACCD has received numerous complaints through the years about access issues people with disabilities have to health and medical services. That is why ACCD became involved in this project. She also explained that ACCD's *Barrier-Free Health and Medical Services in Alberta* project is an initiative to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health services. The *Barrier-Free Health and Medical Services in Alberta* project has two phases. During the first phase, ACCD will be conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Questionnaires have been distributed to people with disabilities and health professionals, and there will be six community consultations at various locations throughout the province. The information collected from the literature review, the questionnaires, and the community consultations will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health and medical services for people with disabilities. In the second phase, ACCD will develop a communications plan and media campaign for disseminating our findings and recommendations to medical professionals, the disability community, and the general public.

Melita began the session by asking participants to introduce themselves by completing the following statement:

> ***The reason I attended this community consultation is…***

The responses were:

- Many personal barriers.
- Referral barriers experienced.
- I am an architect, and I have a lot to offer in regards to universal design.
- General interest in the issues.
- Here to gain more insight into the issues.
- How to make Alberta barrier-free?
- Support for CCSVI (chronic cerebro-spinal venous insufficiency) treatment that the government is not willing to pay for.
- Barriers when entering a building.
- Lack of initiatives by Alberta Health and Wellness to assist people with disabilities in the system.
- I am not able to receive proper x-ray exams.
- People travel to other provinces and countries in order to access appropriate rehabilitation services. We need good services in Alberta.
- Transportation is a barrier for me.

- I have an interest in eliminating barriers to health and emergency room services.
- To bring issues forward experienced by people with a brain injury.
- I am here to bring in the parent perspective and the struggles in navigating the system.
- To identify barriers to medical offices.
- Identify the barriers that people with brain injuries face.
- I am looking for resources.
- I am here to share my experiences about the challenges that blind individuals experience. The need for universal design.
- I am here to present my struggles and to see how I can get some help.
- I want the government to fund and approve medical treatments that are available in other countries.
- To present my struggles in accessing services and prejudice.
- To inform about various education material development.
- To make communities accessible.
- To speak about the issues that people in rural Alberta face every day.
- My challenges with inaccessible exam rooms and medical laboratories.
- How to access mental health supports and services.

Barriers to Accessing Health and Medical Services

Next, participants broke into small groups to discuss barriers when accessing health and medical services, with someone in each group chosen to act as a facilitator. Each member of the group was asked to list the significant barriers that he or she has experienced. Participants were asked to explain the process of how they experience barriers rather than give broad general statements. The barriers were categorized and written on post-it notes.

The post-it notes from each small discussion group were gathered and clustered by themes on flip-chart sheets.

The barriers by theme were:

- **The inappropriateness of the medical system and health professionals**
    - Emergency rooms label individuals. People with disabilities need more understanding and assistance from health professionals when accessing emergency room services.
    - Prejudice within the medical system towards people with disabilities. We are perceived as a burden to the health care system.
    - People with cognitive impairments have a difficult time understanding and comprehending what the health professionals are asking and recommending. Health professionals are not allocating enough time to ensure that people understand what is being told to them.
    - Individuals are being penalized for missing an appointment that has been scheduled over a year ago. Memory issues can lead to this.
    - Staff does not have appropriate knowledge about various disabilities, how to communicate and identify needs, and how to understand behaviours and reactions to situations.
    - Walk-in-clinics should not be a source for primary patient care.
    - Health professionals fail to diagnose medical and social issues.

- Lack of understanding the needs of individuals with learning disabilities.
- Lack of understanding the need for equitable human rights.
- There is a lack of choice of specialists. One specialist serves a large area leaving no option to choose someone else.
- Certain health services are available only to those individuals that fit a very specific criterion.
- Healthcare professionals do not utilize advocates to assist people with disabilities with their health and medical needs.
- People with disabilities are being turned away from emergency departments.
- Lack of appropriate appointment times.
- Lack of lifts in medical clinics to assist in the transfer of patients.
- Shortage of health care professionals who are willing to work and assist individuals with disabilities.
- Transportation is a major barrier when accessing health and medical services in Calgary. Calgary Transit drivers are prohibited from assisting an individual in securing his/her wheelchair.
- Some health care professionals are not able to adapt to the changing nature of health of people with disabilities.
- Attitudinal barriers when accessing health and medical services.
- Healthcare funding for certain disabilities only.
- General practitioners are unwilling to accept new patients with complex needs.
- People with multiple disabilities tend to receive services for one disability need and be denied other necessary services.
- Inaccessible equipment is purchased by health care professionals. People with disabilities experience barriers when they are told to only present one symptom per appointment. Complex needs are not being recognized.
- Healthcare professionals do not understand the system well enough to assist people in accessing necessary services.

- **Government**
  - The Alberta Building Code is not properly enforced.
  - Failure to promote barrier-free and universal design.
  - What is the exact number of people with disabilities in Alberta? Is the government collecting any information in order to allocate adequate resources?
  - There are financial barriers in accessing prescribed medication. In addition, there are barriers in accessing other services like dental, chiropractor or psychologist.
  - Lack of ombudsman for people with disabilities that can lead to policy changes.
  - Many loopholes in jurisdiction process for various programs.
  - How can appeal boards be effective when they lack jurisdiction powers?
  - Service providers need to be consumer driven and held accountable.
  - Increase funding for not-for-profit organizations that assist individuals with disabilities. Include these organizations in the decision-making processes.
  - Lack of statistical information regarding people with disabilities.
  - There is a need for the government to provide appropriate and accessible information on referral to services.

- Lack of media coverage on issues that people with disabilities experience.
- Lack of support with universal design.
- The health care Act needs changes to reflect more of society's current needs.
- Minimum requirements for accessibility need to be raised in order to reflect the needs of the population.

- **Transportation**
  - The Calgary C-Train system has not created an accessible transportation system for people with disabilities. If all platforms were developed with equal heights, then there would not have been the need to install ramps. Instead of poles, straps should be installed for people to hold on to.
  - I do not qualify for Access Calgary, and I am not able to fully utilize public transportation. This makes me unable to go to appointments.
  - Because of the ways Access Calgary works regarding pick up and drop off times, sometimes I have to leave without seeing the doctor.
  - Access Calgary has many issues when accessing certain locations.
  - Lack of accessible taxis. Very few to serve many.
  - Inappropriate available space for wheelchairs in the public transportation system.
  - Accessibility issues with parking meters for people with limited hand functions.

- **Access to services and treatments**
  - People with disabilities have difficulties in accessing and searching for available services.
  - Lack of new education and methods in rehabilitation services.
  - Single-service provider for community services has proven to be an ineffective model because of long wait lists, exclusionary criteria, must fit in certain criteria, and not consumer directed.
  - Long waiting lists.
  - Lack of follow up services after hospitalization.
  - Lack of accessible fitness equipment and facilities necessary for rehabilitation.
  - Many buildings that house certain services are not accessible.
  - Medical exam tables and equipment used for x-rays, bone scans, and other are not height adjustable.
  - Lack of appropriate transfer knowledge.
  - Lack of appropriate services for individuals with mental health and addictions.
  - When a test is performed, people are always told "do not call us, we will call you."
  - Not enough spaces to accommodate individuals with mental health needs.
  - The financial burden that people with disabilities experience for treatments that are not funded by the government.
  - X-ray tables do not have lift apparatus to assist transfer. The case is same with examination tables.

- **Clinics and health care professional offices**
  - There is a lack of standards for clinics and offices when it comes to accessible parking, waiting rooms, and patient rooms. There is an issue with hygiene, as well.
  - The number one barrier is getting through the front door in many places.
  - Without a general practitioner, individuals cannot access mental health services or specialists.
  - There are various disability-specific clinics but they fail to provide the full range of services.
  - The parking stalls are too narrow and the parking meters are not accessible.
  - Exam rooms are very small to accommodate individuals with wheelchairs/scooters.
  - There are no weight scales for individuals in wheelchair/scooter.
  - Lack of height-adjustable examination tables.
  - Reception desks are not appropriately designed for wheelchair/scooter users.
  - Parking cost for medical appointments is so high.

- **Information and referral**
  - There is a difficulty in knowing and accessing where accessible MRI/CAT scan equipment is available.
  - Lack of information and referral services.
  - People tend to be viewed as a nuisance when trying to ask for information and referral services.
  - Lack of essential individual information for people with disabilities.

From Barriers to Solutions

Each of the themes was stated at the top of flip-chart sheets. Each flip-chart sheet had the post-it-notes on it that stated the barriers identified by the participants. The participant groups were asked to go to each flip chart sheet and discuss possible solutions to address the barriers on the post-it notes. When members had reached agreement, they wrote their suggestions on the flip-chart sheet. They moved to the next flip-chart sheet to consider the ideas left by the previous group and added any further solutions.

- **The inappropriateness of the medical system and health professionals**
  - Bringing disability experts and advocates to be part of the medical team.
  - Independent patient advocates who will assist with navigating the system.
  - Recognition of health care professionals that go above and beyond their duties to assist patients.
  - People with disabilities should be an integral part of the decision-making medical team.
  - The health care system needs to be revamped and more flexible.
  - Allow health care professionals the time and resources to develop written reports for patients that have cognitive impairments.
  - Chronic health conditions require a team approach.
  - Ease the transition from child health services to adult health services.
  - Provide educational opportunities for emergency room health professionals regarding mental health issues.

- Assist in the removal of attitudinal barriers by health care professionals to be more patient centred rather then seeing patients as a burden.
- Provide training for health care professionals in dealing with multiple diagnoses.
- Disability-related education and awareness.
- Affordable dental care for low-income Albertans that are not on any program.
- Create a continuous transition between general practitioners and hospital personnel. Communication of medical history and needs.
- Healthcare professionals must be trained in service provision to individuals with mental health, addiction, and sexual trauma.
- Involve peer organizations in the care and consultation.
- Emphasis on health care practitioners and referrals to services.

- **Government**
  - Create a federal act to mandate universal design for new buildings.
  - Enhance media coverage on universal design.
  - All publicly funded buildings should be a subject to an independent design audit.
  - The UN Convention on the Right of Persons with Disabilities requires governments to ensure that all services that are provided for able-bodied individuals be provided to people with disabilities.
  - Appropriate provision of services for people with disabilities will aid with the economic stimulus. These services should not be affected by the changes in the economy.

- **Transportation**
  - Enhance rural handibus transportation so people will be able to utilize rural-Calgary services. There are local rural handibus services, and they need to be able to assist individuals that need to access services in Calgary.
  - If an individual misses a pick-up time because of longer waiting times at a doctor's office, then the government should provide a voucher for accessible taxi services.
  - The municipal government should mediate workshops between Access Calgary and its customers.
  - Encourage the provision of more accessible taxi services.
  - Enhance the design of parking meters for people with limited hand functions.
  - Implement an announcement system on the public transit system.

- **Access to services and treatments**
  - Remove Alberta Health Services hiring freeze in order to increase the number of health professionals assisting patients.
  - Understand that we all will be temporarily handicapped at times during our lives.
  - More support services for individuals who are going through the rehabilitation process and living a life with a disability.
  - Allocate more funds for rehabilitation services.
  - Allow, in extreme cases, home visitations by health care professionals.
  - Staff education in assisting people with disabilities.

- One resource centre that will guide people in accessing services.
- Accessible fitness facilities with proper and accessible equipment.
- Encourage the purchase of medical equipment by health care professionals that is height-adjustable.
- Proper-transfer techniques workshops for health care professionals.
- Develop appropriate programs and services for individuals with mental health and addiction.
- Enhance home care services.
- Financial coverage for treatments that are not offered in Alberta or Canada.
- Assist caregivers in their valuable roles.
- Develop standards for accessible medical equipment.

- **Clinics and health care professional offices**
  - Government Act that will require all buildings, private and public, to be accessible to everyone.
  - Mandate a minimum number of accessible exam rooms per number of patients or health care professionals.
  - Provide incentives for health care professionals to establish practices in accessible offices.
  - Free parking for low-income disabled individuals.
  - Reference to the health care offered in San Paulo.
  - Increase minimal accessibility standards.
  - Allow grants and funding opportunities for health care professionals to make their offices accessible.
  - Centralization of available health services for persons with disabilities that are fully accessible.
  - Accountability for provision of services.
  - Provide training, knowledge, and access to peer support for people who experience mental health, addiction, abuse, and related trauma issues.
  - Provide training, knowledge, and access to peer support for people with developmental disabilities.
  - Universal design awareness campaigns.
  - Establish standards for accessibility for health care practitioner offices.

- **Information and referral**
  - Alberta Health Services needs a listing of information on social media outlets in order to inform individuals about accessible clinics in their areas.
  - Medical receptionists should have proper training in information and referral when working with people with disabilities.
  - Incentives to allow health professionals to develop care manuals.
  - Training for professionals to provide appropriate referrals to available mental health services, addiction, and sexual abuse programs.
  - Information and referral for peer support groups.
  - Information in plain language.
  - Information available in alternative forms.
  - Enhance interpretative services.
  - Health Electronic Records to benefit individuals and at the same time to protect the privacy of individuals.

- Cost of obtaining medical records should be decreased.
- Hiring individuals with disabilities to work in clinics.
- Allow employees to express concerns about lack of services without any reprimands.
- Proper training in making referrals.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. The following community examples were given:

- Dr. Sandy McDonald (Cardiovascular Thoracic Surgeon with ***Barrie Vascular*** Imaging)
- Dr. Kirsty Duncan (international expert on corporate responsibility)
- Sheldon M. Chumir Health Centre
- Alex Seniors Centre
- Dr. Denise Hill (Clinical Assistant Professor for the Department of Clinical Neurosciences, University of ***Calgary)***
- Dr. Stuart Wilkinson
- Dr. Trey Petty (Dentist)
- Ron Semanoff (Calgary Counselling)
- Myrna Schillinger (citizen)

Wrap Up

Attendees were thanked for their participation and asked to contact ACCD if they had any further questions or comments.

Vegreville Community Consultation: A Summary of the Discussion (June 3, 2010)

Opening Remarks

Bev Matthiessen, Executive Director, and Melita Avdagovska, Research and Projects Coordinator, from the Alberta Committee of Citizens with Disabilities welcomed the participants and thanked them for coming to be part of this very important initiative. Bev opened the consultation with an historical perspective of ACCD and the work that is presently being done. She explained that ACCD has received numerous complaints through the years about access issues people with disabilities have to health and medical services. That is why ACCD became involved in this project. She also explained that ACCD's *Barrier-Free Health and Medical Services in Alberta* project is an initiative to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health services. The *Barrier-Free Health and Medical Services in Alberta* project has two phases. During the first phase ACCD will be conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Questionnaires have been distributed to people with disabilities and health professionals, and there will be six community consultations at various locations throughout the province. The information collected from the literature review, the questionnaires, and the community consultations will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health and medical services for people with disabilities. In the second phase, ACCD will develop a communications plan and media campaign for disseminating our findings and recommendations to medical professionals, the disability community, and the general public.

Melita began the session by asking participants to introduce themselves by completing the following statement:

> ***The reason I attended this community consultation is…***

The responses were:

- To express my anger and dissatisfaction with some medical personal who treated me without professional mannerisms.
- To express some of the issues that our clients are experiencing.
- To present some of the barriers that our clients are experiencing when accessing health services.
- To see what others are saying and what I can contribute.
- To present some of the challenges.
- We cover a big area and we are faced with numerous challenges, especially the transition from children to adult services.
- To bring forward some of the FASD concerns.
- To share some of the challenges that young mothers are facing.
- My struggles with the medical professionals and their lack of understanding about filling out forms necessary for benefits.

- To see how I can help my son in his struggles.
- What can we do to enhance supports for people with disabilities when seeking employment?
- To see what other have to say.

Barriers to Accessing Health and Medical Services

Next, participants broke into small groups to discuss barriers when accessing health and medical services, with someone in each group chosen to act as a facilitator. Each member of the group was asked to list the significant barriers that he or she has experienced. Participants were asked to explain the process of how they experience barriers rather than give broad general statements. The barriers were categorized and written on post-it notes.

The post-it notes from each small discussion group were gathered and clustered by themes on flip-chart sheets.

The barriers by theme were:

- **The inappropriateness of the medical system and health professionals**
  - Waiting list for mental health services in Vegreville is 3 months.
  - Individuals on AISH are being charged extra fees from dentists and for eyeglasses.
  - I went to the clinic to talk to my doctor and the receptionist was so rude and did not want to work with me.
  - Always new doctors that need to be educated.
  - There is a shortage of specialists and people must go to Edmonton to access these services.
  - Location of the offices and the hospital are very difficult to get to because of unpaved roads and parking places.
  - Smaller communities surrounding Vegreville do not have any medical and health services so people come here to access what they need.
  - There is a constant turnover of medical and health professionals in the field of FASD.
  - There are 6 doctors in the community but we need at least 12 because the waiting times for appointments are very long.
  - Doctors refuse to fill out forms because they do not know the patient. Then the patient is not able to access programs like AISH or CPP.
  - There is limited acceptance of new patients in some clinics.
  - Staff are afraid to help people to get on the examining table.
  - Lack of appropriate patient history knowledge transfer.
  - Doctors do not have time allocated to fill out forms.
  - Lack of medical technicians. People have to travel to Camrose to access these services.
  - There is big frustration when people go to the doctor because the doctor does not have time to answer all the questions, and they do not provide appropriate directions.
  - Only one issue per appointment.
  - Very short time allocated for appointments.
  - Lack of written care instructions.

- Lack of appropriate training for doctors from different countries.
- Lack of treatment consistencies between doctors educated in Canada and doctors educated in other countries.

- **Access to services**
  - People have to wait too long in order to access medical tests.
  - Lack of transition from child to adult services. Pediatric medical professionals understand disabilities like autism, but when a child turns 18, finding a doctor that understands autism is very difficult.
  - When creating services, there is a disability priority selection. Cancer patients get higher priority but other needs do not.
  - There is a lack of psychiatric services.
  - No assistance in explaining and reviewing prescribed medications.
  - Lack of appropriate service provision by AADL and when a client needs to contact a vendor.
  - People from Vegreville and surrounding areas travel to Edmonton for services.
  - How to afford medication that is prescribed by a physician but not on the formulary?
  - How long do we have to wait for cataract surgery? Then we wait for a bed.
  - When individuals are not able to obtain diagnosis in a timely manner, then they are not able to access services.
  - Because of lack of mental health services, people end up in the jail, on the street, or in the hospital.
  - Many financial barriers are in place now that prevent people from accessing services.
  - Waiting two years to diagnose.

- **Transportation**
  - There is a lack of appropriate transportation system in Vegreville. People have to rely on their families, friends, and neighbours if they are to get to any kind of services. There is only one set transportation system but individuals can only access it in Vegreville. Many not-for-profit organizations are using resources to assist individuals in accessing transportation to get to medical appointments.
  - Here transportation is very costly.
  - Buses no longer run when people need them. The impact of Greyhound cutting services is very profound.
  - There is no transportation system to Camrose where most of the medical appointments are being set up.
  - People that go to St. Paul experience lack of parking stalls and people that travel to Edmonton have to pay large sums for parking.
  - How can people go to appointments in Edmonton, when they have to pay for accommodations?
  - Lack of appropriate transportation for seniors.

- **Physical accessibility**
  - Examining rooms are very small and there is insufficient space for wheelchair users.

- Most of the clinics do not have automated door openers, and the entrance doors are very heavy.
- Doctors do not own the clinics so they tend to rent a space that is affordable rather than accessible.

- **Attitude, communication, and community advocates**
  - There is a great challenge with doctor attitudes toward people with disabilities.
  - Health professionals are unwilling to assist people with filling out forms necessary for funding programs.
  - Clients need to have advocates with them when going to appointments because doctors do not give easily understood directions.
  - Doctors from other countries have different expectations and treatments.
  - Every time a new doctor comes, needs to be trained.
  - People that are trying to get on AISH cannot get support from the medical personnel.
  - There is a lack of appropriate referral and advocacy.
  - Lack of plain language.
  - Lack of understanding guardianship.
  - FASD is misunderstood and often leads people to live in poverty.

From Barriers to Solutions

Each of the themes was stated at the top of flip-chart sheets. Each flip-chart sheet had the post-it-notes on it that stated the barriers identified by the participants. The participant groups were asked to go to each flip chart sheet and discuss possible solutions to address the barriers on the post-it notes. When members had reached agreement, they wrote their suggestions on the flip-chart sheet. They moved to the next flip-chart sheet to consider the ideas left by the previous group and added any further solutions.

- **The inappropriateness of the medical system and health professionals**
  - Eliminate the pay scale difference between urban and rural doctors.
  - Enhance the rural Alberta recruiting program.
  - Create incentives for health professionals to come and work in rural areas.
  - There is a drop-in clinic in Viking and it works very well.
  - Eliminate operator machine telephone system.
  - Create access to medication that is appropriate and necessary for individuals.
  - Inform health professionals on how to give clear directions.

- **Access to Services**
  - Rapid access to services.
  - More specialists in adult services.
  - When a child is transitioning to adult services, then the pediatrician needs to keep the patient until proper services are set up in the adult world.
  - The transition of services between age 18 to 65 and 65 and over should be connected and seamless for the individual in the system.
  - The ability to set up a program in Vegreville that will perform day surgeries which will cut down waiting time and people will be able to receive timely and appropriate services in their own communities.

- Set up of specialized traveling clinics for mammograms, bone density, foot, hearing aid, etc. They work very well and people appreciate the access.

- **Transportation**
  - Money to initiate a program that will provide appropriate and necessary transportation services.
  - Transportation connection between smaller communities.
  - The Vegreville Transportation System to be enhanced.
  - Municipalities to start taking on the responsibility for appropriate transportation.
  - Information and referral program about transportation services.
  - To see how volunteers can be drivers.

- **Physical accessibility**
  - Standards should be set about accessibility in doctor's offices.
  - The government should provide incentives to encourage medical clinics to be accessible.
  - New buildings should comply with the Alberta Building Code and create barrier free designs.
  - Doctors should have accessible exam rooms.

- **Attitude, communication, and community advocates**
  - Sensitivity training offered to health professionals.
  - To establish a good referral's system to community resources.
  - Education and awareness regarding various disabilities.
  - Health professionals should use community advocates to assist them in helping people.
  - Education and awareness about the usage and benefits of plain language.
  - Advocates play the role of an interpreter of the doctor orders.
  - There should be campaigns to recruit more volunteers.
  - The government should invest in building the natural support system. This will lead to long term investments.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. During this community consultation, none were provided.

Wrap Up

Attendees were thanked for their participation and asked to contact ACCD if they had any further questions or comments.

Rocky Mountain House Community Consultation: A Summary of the Discussion (June 4, 2010)

Opening Remarks

Bev Matthiessen, Executive Director, and Melita Avdagovska, Research and Projects Coordinator, from the Alberta Committee of Citizens with Disabilities welcomed the participants and thanked them for coming to be part of this very important initiative. Bev opened the consultation with an historical perspective of ACCD and the work that is presently being done. She explained that ACCD has received numerous complaints through the years about access issues people with disabilities have to health and medical services. That is why ACCD became involved in this project. She also explained that ACCD's *Barrier-Free Health and Medical Services in Alberta* project is an initiative to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health services. The *Barrier-Free Health and Medical Services in Alberta* project has two phases. During the first phase, ACCD will be conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Questionnaires have been distributed to people with disabilities and health professionals, and there will be six community consultations at various locations throughout the province. The information collected from the literature review, the questionnaires, and the community consultations will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health and medical services for people with disabilities. In the second phase, ACCD will develop a communications plan and media campaign for disseminating our findings and recommendations to medical professionals, the disability community, and the general public.

Melita began the session by asking participants to introduce themselves by completing the following statement:

> ***The reason I attended this community consultation is…***

The responses were:

- To learn what everyone is experiencing.
- So far I have found doctors very supportive and accessibility is very good.
- I want to know about the upcoming issues that might affect me.
- Why don't doctors do home visits? During winter, it is very difficult for me to access health services.
- Here to learn and contribute.
- To see what others are saying.
- Came to participate.
- To learn.
- I have experienced barriers with the home care system. Many attitudinal barriers.
- We have to travel in order to access services.
- There are challenges to accessing basic health care.
- Issues with physical accessibility.

Barriers to Accessing Health and Medical Services

Next, participants broke into small groups to discuss barriers when accessing health and medical services, with someone in each group chosen to act as a facilitator. Each member of the group was asked to list the significant barriers that he or she has experienced. Participants were asked to explain the process of how they experience barriers rather than give broad general statements. The barriers were categorized and written on post-it notes.

The post-it notes from each small discussion group were gathered and clustered by themes on flip-chart sheets.

The barriers by theme were:

- **The inappropriateness of the medical system and health professionals**
  - There are no specialists here. People have to travel to Red Deer to access these services.
  - If an individual needs mental health supports in Rocky Mountain House, he/she is told to wait 90 days or go and access services in Red Deer.
  - People need to fight in order to get a pacemaker.
  - Health professionals put off tests for seniors, because "they do not have long to live."
  - We have to do research before we go to the doctor's office.
  - Doctors do not use plain language when giving directions.
  - We advocate for people to take someone with them when going to the doctor.
  - People with disabilities are last to receive care in the emergency room.
  - If you go often to the ER, they make you wait more than anyone else.
  - Medical staff at the laboratory ignore abuse complaints.
  - Everything is rushed.
  - People with chronic conditions cannot go and see their doctor for all their needs. One symptom per visit.
  - Wait times are too long for services.

- **Access to services**
  - Red Deer is where people from Rocky Mountain House try to access services, but it is very booked as well.
  - Poor access to family doctor.
  - Wait time is too long for many services.
  - There is one x-ray room, so wait times for appointments are very long.
  - Mental health services are being accessed in Red Deer.
  - Jumping through various hoops in order to access mental health services.
  - There are two reserves outside of Rocky Mountain House and the individuals living there are also struggling with accessing services.
  - People use the ambulance very frequently because of the lack of appropriate transportation.
  - Referrals to specialists are in Red Deer.
  - The 'good' doctor in the community is backed up because everyone is waiting to see him.
  - The MS clinic is in Red Deer and because of the transportation costs the MS Society is offering some financial relief.

- Travelling mammogram service comes once a year.
- The parking lot at most of the clinics is not paved so that creates accessibility barriers.
- There are no services for people that suffer a stroke.
- Because of inappropriate long term care and supportive living accommodations, people are transferred away from their communities.
- Support staff are asked to sit with the person with a disability after surgery, rather than have medical staff do it.
- 3 months to get on AISH.
- There is a poor mental health network.
- Lack of appropriate community follow up by medical staff.
- Health professionals do not like the community organizations that help people with disabilities.

- **Transportation**
  - There is a van available at the Good Sam that is supposed to be for community use; however, it is not being shared.
  - There is no transportation system that is accessible and affordable.
  - People incur very high transportation costs.

- **Advocacy**
  - In Rocky Mountain House, advocates are doing all the work.
  - Advocates have to act as detectives in order to assist their clients.
  - There is lack of a standard processes when assisting people with disabilities.
  - There are no home visits.

- **Attitudes**
  - Negative attitudes toward people with disabilities.
  - "Those people."
  - Attitudes toward individuals with mental health that "we do not deal with people like that."
  - Negative attitudes at medical clinics – "what is wrong with him?"
  - "No need to help because he will die anyway."
  - Lack of appropriate bed-side manners.

- **Financial barriers**
  - The accommodation fees at the long term care facilities have increased.
  - The cost for long term and supportive living accommodations is higher than the pension.

- **Housing**
  - Lack of affordable and accessible housing.
  - People with mental health issues are living in tents; they are falling through the cracks.
  - Many people are homeless because of lack of services.

- **Physical Accessibility**
  - The weight of the doors and how they are installed creates a barrier for people.

- Clinics in Rocky Mountain House are not very accessible. Even the door to the elevator is not user-friendly.
- The travelling bus for mammogram services is not accessible for people with disabilities.
- Lack of accessible sidewalks.

- **Equipment**
  - Lack of appropriate design.
  - Backpacks need more space so assumed accessibility is no longer enough.

- **Home care, caregiver, and respite care supports**
  - There are five nurses that do the assessments.
  - It takes more than 3 weeks to have someone do the assessment.
  - Lack of homemaking options.
  - No support for caregivers.
  - No respite care services.
  - No respite care beds.
  - Nothing in place to assure appropriateness of caregivers.
  - No caregiver incentives.
  - Families need support and the system does not assist them.
  - There are financial and emotional burdens.
  - High time demands.

From Barriers to Solutions

Each of the themes was stated at the top of flip-chart sheets. Each flip-chart sheet had the post-it-notes on it that stated the barriers identified by the participants. The participant groups were asked to go to each flip chart sheet and discuss possible solutions to address the barriers on the post-it notes. When members had reached agreement, they wrote their suggestions on the flip-chart sheet. They moved to the next flip-chart sheet to consider the ideas left by the previous group and added any further solutions.

- **The inappropriateness of the medical system and health professionals**
  - There should be a medical team with various specialists set up in every community so people do not have to travel in order to access services.
  - Standards for practice set up.
  - Education and awareness regarding various disabilities and accessible medical equipment usage.
  - Thinking in advance – planning from the beginning.
  - Doctors need to do home visits for people that cannot access transportation.
  - Incentives to attract more doctors in rural areas.

- **Access to services**
  - Discharge follow-up with education and awareness.
  - Eliminate criteria that prevent people from accessing supports.
  - Traveling specialist medical teams to come to Rocky Mountain House on bi-weekly or monthly basis.
  - Infrastructure for health services to be set up so people can access services in their communities.

- Install lifts to assist people to transfer.
- Usage of equipment by all that have a need.

- **Transportation**
  - Grants to assist with transportation expenses.
  - Vouchers for people to access transportation to and from medical exams.
  - Incentives for the local taxi services to have accessible transportation.
  - Doctors should do home visits and cut down on the wait times.
  - Create a community access transportation system in Rocky Mountain House.

- **Advocacy**
  - Create a cross-disability information and referral navigator.
  - Allow individuals to lodge complaints without fear of reprimands.
  - Educate people with disabilities about how to lodge a complaint.
  - Create advocacy groups for individuals that do not belong to any organization.
  - Establish uniform advocacy processes for community organizations.
  - Establish a ParticipAction campaign.

- **Attitudes**
  - Develop strategies to raise awareness about people with disabilities.
  - Create a tool that will allow disability knowledge sharing among health professionals.
  - Teach people how to inform health professionals about situations – "You do not want this to happen but it has happened."
  - "Stand in our shoes to understand why we want and demand services."
  - Challenge the medical staff to understand the need.
  - Community organizations to act as an information resource.
  - We can all be teachers.

- **Financial barriers**
  - Invest in appropriate and necessary services.
  - Educate policy makers to differentiate between need versus not vital spending.

- **Housing**
  - Establish a homeless shelter in Rocky Mountain House.
  - Create incentives for builders to build affordable and accessible housing options.
  - Incentives to sustain affordable and accessible housing.

- **Physical Accessibility**
  - Create a rating scale for accessibility among the doctors.
  - Awareness through the media.
  - A "concern's line" where people can call and express barrier issues, so there is a continuous record of issues.
  - Initiatives to create accessible streets.

- **Equipment**
    - Develop appropriate equipment according to the needs of the individual (manufacturing and design).
- **Home care, caregiver, and respite care supports**
    - Programs that will help caregivers to understand the needs of the individuals and how to cope and manage with the caregiving demands.
    - Create programs that will assist caregivers to navigate the system.
    - Provide family supports to assure continuation of care.
    - Information and referral system.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. During this community consultation, none were provided.

Wrap Up

Attendees were thanked for their participation and asked to contact ACCD if they had any further questions or comments.

Lethbridge Community Consultation: A Summary of the Discussion (June 7, 2010)

Opening Remarks

Melita Avdagovska, Research and Projects Coordinator, from the Alberta Committee of Citizens with Disabilities welcomed the participants and thanked them for coming to be part of this very important initiative. Melita opened the consultation with an historical perspective of ACCD and the work that is presently being done. She explained that ACCD has received numerous complaints through the years about access issues people with disabilities have to health and medical services. That is why ACCD became involved in this project. She also explained that ACCD's *Barrier-Free Health and Medical Services in Alberta* project is an initiative to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health services. The *Barrier-Free Health and Medical Services in Alberta* project has two phases. During the first phase, ACCD will be conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Questionnaires have been distributed to people with disabilities and health professionals, and there will be six community consultations at various locations throughout the province. The information collected from the literature review, the questionnaires, and the community consultations will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health and medical services for people with disabilities. In the second phase, ACCD will develop a communications plan and media campaign for disseminating our findings and recommendations to medical professionals, the disability community, and the general public.

Melita began the session by asking participants to introduce themselves by completing the following statement:

> ***The reason I attended this community consultation is…***

The responses were:

- To represent a person with a disability.
- To identify problems and see what this consultation is all about.
- To represent my client and to learn more.
- I live with a disability.
- Working with people with disabilities and assisting them in accessing health services.
- To gather more information.
- I have a grandson with a disability living on his own, and I want to see what others are doing.
- Assist people with disabilities who are seeking employment opportunities and bring forward some of the issues.

- Clients are experiencing physical and health barriers.
- To gather more information.
- To bring forward the concerns of the hard of hearing community.
- I am a self-advocate, and I came to share some information.
- I am here on behalf of brain injury clients and to present some of the communication barriers.
- To learn more about the issues.
- I am facing many barriers at doctor's offices and universal design implementation is my goal.
- The MS advisory council wants to see equal access to resources regardless of disability. In Lethbridge, there is a lack of resources like housing and transportation.
- To hear what others have to say and gather more knowledge.
- To present my issues.
- To bring my issues forward.
- To see what is happening.
- To offer support.

Barriers to Accessing Health and Medical Services

Next, participants broke into small groups to discuss barriers when accessing health and medical services, with someone in each group chosen to act as a facilitator. Each member of the group was asked to list the significant barriers that he or she has experienced. Participants were asked to explain the process of how they experience barriers rather than give broad general statements. The barriers were categorized and written on post-it notes.

The post-it notes from each small discussion group were gathered and clustered by themes on flip-chart sheets.

The barriers by theme were:

- **The inappropriateness of the medical system and the health professionals**
    - If you do not appear disabled enough, doctors do not offer any assistance.
    - There is an issue with doctors constantly moving and leaving.
    - No consistent family physicians, especially in the rural areas around Lethbridge.
    - Doctors are unable to take on patients with complex and unique conditions.
    - Health professionals lack appropriate disability-related knowledge.
    - There is a lack of medical specialists.
    - Medical professionals have a poor understanding of the implications of hearing loss.
    - Lack of knowledge regarding how to speak to a person who is hard of hearing.
    - Long waiting times for appointments.
    - Lack of support in the emergency room for people with developmental disabilities and the behaviours.
    - No or limited speech therapists, O.T.'s or physical therapy specialists in the rural communities.
    - The language that doctors use is very difficult to understand.
    - Long waiting lists to access specialists.
    - Doctors interviewing new patients and refusing patients with complex cases.

- There are difficulties in finding a doctor who will assist individuals to fill out medical assessments necessary for access to services.
- There are various policies that cause many issues for people with disabilities – when outside is -30C, people still have to show up at the doctor's office in order to renew their prescriptions.
- No lifts at doctor offices and staff does not have knowledge of how to conduct appropriate transfers.
- It is very difficult to understand what is being said during a medical exam.
- Lack of assisting staff during appointments.
- Lack of doctors that take the time to listen to their patients.
- Need more trustworthy doctors.

- **Access to services**
  - Radiology rooms too small for wheelchair users.
  - No transfer teams available.
  - Cuts to previously-covered services.
  - Lack of screening for conditions that might require additional supports. People need to access services from the beginning.
  - Need better integration of service providers and easier transfer of medical information.
  - Hospital staff does not want to acknowledge that people face barriers when they are hard of hearing.
  - People that need to be placed in long term care facilities are moved away from the community.
  - Lack of medical services leads people to move to bigger cities in order to access services.
  - Adults with developmental disabilities who do not meet the PDD criteria face many barriers.
  - No supports or services for some disabilities.
  - No ongoing rehabilitation programs and services for people on CPP or AISH.
  - Lack of adequate in-home support for young adults.
  - Limited funding for rehabilitation programs.
  - Barriers to accessing mental health services – long waiting lists, no referral or refusal to do a referral.
  - The cost of neuropsychiatric or psychiatric assessments for those on limited income.
  - Huge service gaps for those with disabilities between the ages of 18 to 65.
  - No easy access to interpreters for individuals with hearing impairments.
  - Many treatments that are available in other countries are not available in Canada/Alberta.
  - One specialist has to see more than 40 patients a day.
  - Some services are only partially covered, and some not at all.
  - Lack of funding for necessary medical needs.
  - Not enough financial support to pay for medical services.
  - Too many medication errors by pharmacies.
  - Eye prescriptions and eyewear are very expensive.
  - High cost of staying in the hospital.

- **Transportation**
  - HandiBus schedule is unreliable.
  - There is not enough seating space for wheelchair users or obese people on the public transportation system.
  - Because of lack of appropriate public transportation, many individuals are not able to access appointments in a timely manner.
  - There are no means of transporting non-ambulatory individuals to medical centers or between departments at hospitals.
  - There is a lack of adequate transportation in the surrounding rural areas.
  - Without appropriate transportation, individuals are not able to access a doctor or the emergency department.
  - Transportation expense after discharge at another location is often the responsibility of the individual.
  - Lack of late night transportation to emergency services.

- **Advocacy**
  - Lack of advocates because of funding barriers.

- **Housing**
  - Lack of affordable and accessible housing for people with disabilities.

- **Physical Accessibility**
  - Doors are too heavy to pull open.
  - In the older sections of the city, sidewalks do not have curb cuts.
  - Often the elevators at the hospital are not working and people cannot use the stairs.
  - Entrance to buildings and medical offices are often inaccessible for wheelchair users.
  - Most of the time, automatic doors are locked so people are not able to access the entrance.
  - Not having an accessible path of travel for people with visual impairments.
  - Lack of accessible washrooms.
  - Many places lack ramps.
  - Specialized equipment not readily available, even in medical facilities.
  - No railings on the stairs for support.

- **Equipment**
  - AADL/government funding does not continue to pay equipment expenses when the client turns 18 (for example, hearing aids).
  - Costs for equipment. Basic hearing aids are so expensive, and they are not covered by various assistance plans.
  - Lack of timely approval for wheelchairs for people that depend on this equipment.
  - Limited or insufficient funding for AADL supplies.

From Barriers to Solutions

Each of the themes was stated at the top of flip-chart sheets. Each flip-chart sheet had the post-it-notes on it that stated the barriers identified by the participants. The participant

groups were asked to go to each flip chart sheet and discuss possible solutions to address the barriers on the post-it-notes. When members had reached agreement, they wrote their suggestions on the flip-chart sheet. They moved to the next flip-chart sheet to consider the ideas left by the previous group and added any further solutions.

- **The inappropriateness of the medical system and health professionals**
  - Appropriate access to medications.
  - Incentives to recruit more doctors.
  - Younger individuals to be encouraged to enter the medical field.
  - Appointments should be according to time needs (shorter for prescription renewal and longer for more complex needs).
  - Pharmacist should play a bigger role in the education of patients about proper medication usage.
  - To accept people regardless of the complexity of their disability.
  - Provide financial reimbursement to doctors for filling out medical forms necessary to access services.
  - Enhance mental health services.
  - Inform people with disabilities about organizations and advocates that can help them out to fill out forms.
  - Incentives for doctors to take on educational and awareness workshops regarding various disabilities.
  - Fix the billable hour's concept.
  - Any therapy prescribed by a specialist or a doctor should be subsidized and available to the individuals that are low-income or living on AISH.
  - To remove the assumptions that Lethbridge is a rural community.

- **Access to services**
  - Portability of services.
  - Removal of funding caps.
  - Satellite medical clinics and having facilities set up to offer these traveling services.
  - Establish rehabilitation services.
  - Recruit specialists that can assist many individuals.
  - Enhance community-based medical services.
  - Create a funding opportunity for the University of Lethbridge to establish a movement clinic.
  - Prevent movement of services to Calgary.
  - Have an individual from Lethbridge that will sit on the Alberta Health Services board.
  - Patient should not pay for equipment when it is being purchased by medical staff.
  - Dentists now require a credit card on file. Many low income individuals cannot afford additional expenses.

- **Transportation**
  - Assure a transportation system that will respond to medical appointment needs.
  - Establish incentives for taxi companies to have accessible taxis.

- Education and awareness about what is considered accessible transportation.
- Mandate accessible taxis for each taxi company.

- **Advocacy**
  - Decision makers to grasp the diversity of each location.
  - To challenge doctors and decision makers to understand barriers.
  - Education and awareness.
  - Disability should be federal so there is consistency in the message.
  - Funding for legal representation concerning disability issues.

- **Housing**
  - All architects should be educated in universal design.
  - Create independent living possibilities for people with disabilities who would like to remain in the community.

- **Physical Accessibility**
  - Building inspectors to enforce the Alberta Building Code.
  - Funding for health professionals to purchase accessible medical exam tables.
  - Standards for accessible clinics.
  - Incentives for doctors to renovate their clinics and create accessible environments.
  - Purchase height-adjustable equipment.
  - Lifts in exam rooms to assist with patient transfers.

- **Equipment**
  - Appropriate assessments to be conducted.
  - Vendors to be screened.
  - Allow people to obtain appropriate equipment and enhance their quality of life.
  - Allocated equipment should be updated and reflect the needs of the individual.
  - Timeline usage to be decreased. It is very inefficient to have one hearing aid for every five years.
  - Enhance cost sharing.
  - Transparent appeal process for AADL.
  - Programs that will cover all parts of assistive technologies and not just some parts.

Other issues

Participants raised the following additional barriers:

- Hotels do not have accessible accommodations when people have to travel to access medical appointments.
- Hotel rooms are not equipped for people with disabilities and their care attendants.
- Limited amount of flexible employment for people with disabilities.
- Difficult to survive on the AISH monthly allowance.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. The following community examples were given:

- Dr. Longhail (Bigelow Fowler West)
- Dr. Coma (Family Medical)
- Dr. Ron Tuzjikawa
- Dr. A. Smith (Bigelow Fowler Clinic)
- Dr. Meyer (#2, 1718 3 Avenue S)
- Dr. Daniel Steves (Bigelow Fowler South Clinic)
- Dr. Ikuto (Geriatrics)
- Dr. Mike T Neurosurgeon Foothills Medical Center

Wrap Up

Attendees were thanked for their participation and asked to contact ACCD if they had any further questions or comments.

Grande Prairie Community Consultation: A Summary of the Discussion (June 11, 2010)

Opening Remarks

Melita Avdagovska, Research and Project Coordinator, from the Alberta Committee of Citizens with Disabilities welcomed the participants and thanked them for coming today to be part of this very important initiative. Melita opened the consultation with an historical perspective of ACCD and the work that is presently being done. She explained that ACCD has received numerous complaints through the years about access issues people with disabilities have to health and medical services. That is why ACCD became involved in this project. She also explained that ACCD's *Barrier-Free Health and Medical Services in Alberta* project is an initiative to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health services. The *Barrier-Free Health and Medical Services in Alberta* project has two phases. During the first phase, ACCD will be conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Questionnaires have been distributed to people with disabilities and health professionals, and there will be six community consultations at various locations throughout the province. The information collected from the literature review, the questionnaires, and the community consultations will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health and medical services for people with disabilities. In the second phase, ACCD will develop a communications plan and media campaign for disseminating our findings and recommendations to medical professionals, the disability community, and the general public.

Melita began the session by asking participants to introduce themselves by completing the following sentence:

> ***The reason I attended this community consultation is…***

The responses were:

- Removal of barriers is one of our priorities.
- I am extremely upset because of the lack of services in the area. Something has to be done.
- Here to learn.
- I am interested to learn what others are saying. I am frustrated about the various barriers that I am seeing.
- To talk about the lack of specialists and services.
- I am here to talk about how difficult it is to find a clinic that is accessible. Staff does not know how to transfer me.
- To gather information.
- I am here to share information. We have not been able to find a family doctor for several years.
- I am frustrated with the lack of transition services for children that turn 18.
- To find out more about what is happening in this community.

- To listen to the concerns.
- Here to present some of the barriers that our clients are experiencing.

Barriers to Accessing Health and Medical Services

Next, participants broke into small groups to discuss barriers when accessing health and medical services, with someone in each group chosen to act as a facilitator. Each member of the group was asked to list the significant barriers that he or she has experienced. Participants were asked to explain the process of how they experience barriers rather than giving broad general statements. The barriers were categorized and written on post-it notes.

The post-it notes from each small discussion group were gathered and clustered by themes on flip-chart sheets.

The barriers by theme were:

- **The inappropriateness of the medical system and health professionals**
  - Lack of psychiatrists who are trained in developmental disabilities and willing to treat them.
  - Doctors present negative attitudes toward people with disabilities, lack of knowledge.
  - Doctors are strapped for time and training.
  - Many health professionals are not aware about disability-related behaviour or therapies.
  - People are being sent home without explaining how to use equipment.
  - Doctors are affected by the cutbacks and the patients are experiencing the consequences.
  - Inappropriate bedside manner with people with developmental disabilities.
  - Doctors are not listening to patients to understand their needs.
  - Lack of recruitment of doctors for family practice.
  - Lack of appropriate funding necessary for health professionals to train and improve their knowledge.
  - Doctors are under pressure to see many patients every day.
  - Doctors are not taking complaints seriously from people with developmental disabilities.
  - High turnover rate of doctors.
  - Doctors are not willing to stay very long in areas like Grande Prairie.
  - Lack of trained staff to work with people with complex needs.

- **Access to services**
  - People with developmental disabilities are being denied access to psychiatric services at the hospital while everyone else with same symptoms gain admission to acute care.
  - Lack of psychiatric services for children in acute care.
  - Lack of access to neurological services.
  - People have to travel to Edmonton in order to access services.
  - More impaired an individual – less available services.
  - Lack of specialized equipment services.
  - No emergency placement for people lacking family support.

- Services for individuals that are living off the reserves are virtually non-existent.
- Lack of collaboration between PDD and Alberta Health Services.
- Lack of funding to conduct appropriate assessments.
- People are not able to access services because of attitudinal barriers.
- Access to services has been compromised because of cuts to funding.
- People who try to access services outside of Grande Prairie have to bear the cost of the travel.
- "A person with 69 IQ is living comfortably, while a person with 71 IQ is on the streets."
- People are "surviving but not thriving."
- Neglect and abuse.
- Unrealistic timelines and lack of financial support to meet mandated standards imposed by funders.
- Lack of transparent information of how budget allocations are being used.
- Lack of access to necessary medical equipment.
- Lack of mental health services available for families of people with disabilities.
- People leave by air ambulance or ambulance to Edmonton and upon release from the hospital they have to pay for their transportation back.
- Very long wait lists for diagnosis and treatment services.
- Lack of transition planning services for young adults 17 to 18 years old.
- Walk-in clinics have very long wait times.
- Very high parking fees.
- Lack of appropriate responses to referrals.
- Many issues with WCB and access to services.
- Financial assistance is not accessible equally throughout the province. Local management determines what their office will pay for.
- People are being released from the hospital without ensuring that they have a support system.

- **Transportation**
  - Lack of organizations that can assist people with disabilities to and from medical appointments.
  - People who live outside of Grande Prairie have difficulties accessing transportation to and from medical appointments.
  - In Grande Prairie, there are limited numbers of DATS buses, and it is very difficult to access them in a timely manner.
  - Ambulances are used because there is no appropriate accessible transportation system.

- **Advocacy and community organizations**
  - People have to constantly search through various organizations in order to see who offers what services.
  - Lack of communication between organizations.
  - Organizations want to do more but there is a lack of opportunities and funding.
  - Lack of unified national disability voice.
  - Organizations are not sure how to create action.

- **Caregivers and family members**
  - Lack of financial support for caregivers.
  - Lack of respite care services.
  - Lack of training and support services for family members that provide care.

- **Physical Accessibility**
  - Lack of height-adjustable exam tables at doctor's offices.
  - Sidewalks are not accessible for wheelchair users.
  - Parking not properly used.
  - There are many physical barriers that prevent people from entering doctor's offices.

- **Information and resource navigation**
  - People are referred from one place to another and back and forth.
  - Lack of cooperation among professionals to make people aware of resources that are available in their communities.
  - FSCD plays a guessing game about telling people what it can fund and what it cannot.
  - Referrals cost money to families.
  - Lack of meaningful and incorporated participation of clients, caregivers, and families.

- **Disability awareness**
  - Health professionals lack the understanding of decision-making rights and guardianship.
  - Person has to look disabled in order to qualify for a program.
  - Lack of disability-related education and awareness.

- **Financial Barriers and Employment**
  - People who choose to work in the disability field cannot afford to live off the wages this sector pays. Consequently, there are too many undereducated front line staff working in this sector.
  - People who are on AISH or CPP struggle to afford basic necessities.
  - People do not want to be poor and left out.

From Barriers to Solutions

Each of the themes was stated at the top of flip-chart sheets. Each flip-chart sheet had the post-it-notes on it that stated the barriers identified by the participants. The participant groups were asked to go to each flip chart sheet and discuss possible solutions to address the barriers on post-it notes. When members had reached agreement, they wrote their suggestions on the flip-chart sheet. They moved to the next flip-chart sheet to consider the ideas left by the previous group and added any further solutions.

- **The inappropriateness of the medical system and health professionals**
  - Enhance the work between health professionals, Alberta Health Services, and Alberta Health and Wellness.
  - Incentives for students to go into the medical profession.

- Broaden the concepts for diagnosis and treatments in order for people to be able to access appropriate services.
- Offer disability-appropriate training for health professionals.
- Create a strategic plan of how to get more health professionals to move to Grande Prairie and remain long term.
- Enhance rural recruitment of health professionals.

- **Access to services**
  - Enhance services in smaller communities.
  - Ensure funding for information and referral services.
  - Education and understanding about why referral services are necessary.
  - Create additional traveling specialist clinics.
  - Improve the support system for accessing services that are not offered in Grande Prairie.
  - People should be allowed medical appointment days when they need to travel outside of Grande Prairie when accessing medical appointments and services.
  - Appropriate and timely access to medical services.
  - Discharge planners who will assist people to integrate back into the community.
  - Government departments that are committed to collaboration.
  - Establish a community resource centre that will offer counselling, support, advocacy, and resources.

- **Transportation**
  - Increase the number of accessible transit busses.
  - Create a transportation system that it is accessible and timely.
  - Create an efficient booking system for DATS.

- **Advocacy and community organizations**
  - Enhance the volunteer service sector.
  - Organizations need to take on the responsibility of updating the information that they provide.
  - All organizations need to unite and create one point of access for people that are looking for help.

- **Caregivers and family members**
  - Create a pool of staff that will be able to provide respite care services to people.
  - Enhance support groups.
  - Flexibility for staff that care for more than one client.
  - Create funding methods for family caregivers to be able to access respite care services.
  - Improve respite care services.
  - Create opportunities for caregivers to be paid for the services they provide.
  - Create a tool that will allow sharing of tips and services.

- **Physical Accessibility**
  - Create standards for accessible clinics and equipment.
  - Educate on universal design.
  - There should be at least one place that is fully accessible.

- **Information and resource navigation**
  - One point of access – creation of a community connector.
  - More information sharing about funding programs – people need to know what exactly is being funded.
  - Programs are being shut down without informing everyone in the system.
  - There should be knowledge sharing sessions about funding criteria.
  - Improve the assessment system and remove the financial barriers associated with it.

- **Disability awareness**
  - There should be more disability awareness presentations and follow up.
  - There should be new research information sessions. People should be able to know what is out there as a therapy possibility.
  - Enhance the methods of how verification of disability is done. The system has to be appropriate.
  - Educate court employees about disability-related behaviour.

- **Financial Barriers and Employment**
  - People want to have appropriate housing, food, health, and be able to participate in society as contributing citizens.

Community Exemplars

As a final exercise, attendees were asked to provide names of physicians/clinics/organizations that work toward barrier-free health and medical services in their communities. The following community examples were given:

- Bonnie Sunde, teacher at Crystal Park School
- Connie Pilgrim, teacher at Crystal Park School
- Dr. James Pope
- Employers: Sears and the Daily Herald Tribune
- Bryan Zacharious, Goodwill support worker
- Dr. Chip Ingraham, dentist
- Dr. Brad Martin
- Dr. Alexandra Noga
- Dr. Richard Martin
- Karla Sondrup, nurse
- Curtis Crough, pharmacist

Wrap Up

Attendees were thanked for their participation and asked to contact ACCD if they had any further questions or comments.

Appendix II: Health Professionals and People with Disabilities Surveys

Health Professionals Survey

Dear Health Professional:

You are invited to participate in a research study to identify the barriers that Albertans with disabilities face when accessing preventative and ongoing health and medical services.

The Alberta Committee of Citizens with Disabilities is a consumer-directed provincial cross-disability organization that has worked since 1973 to promote full participation in society for Albertans with disabilities. ACCD recently received a grant from the Alberta Human Rights and Multiculturalism Fund for a project entitled Barrier-Free Health and Medical Services in Alberta.

As part of this study, we are conducting a systematic literature review to identify existing research, policies, case studies, government initiatives, legislation, and opinions on the state of access to health and medical services for people with disabilities. Information is also being gathered through questionnaires that have been distributed to health professionals and people with disabilities. In addition, we will be hosting focus groups at various locations throughout the province. The information collected from the literature review, the questionnaires, and the focus groups will be used to identify issues, develop strategies, and produce recommendations for creating inclusive, accessible health and medical services for people with disabilities.

Our advisory committee is comprised of government personnel, medical professionals, disability community representatives, and various experts in the field of health and medical services delivery.

The survey is ANONYMOUS! The information gathered is confidential and will not be shared with any other organization or regulatory body. There are no costs or risks to you for filling out the questionnaire.

Your answers will help us identify YOUR NEEDS as a health professional when providing health and medical services to Albertans with disabilities. Your participation is voluntary.

The survey should take about 15 minutes to complete. We ask that you complete and return it by June 30, 2010 in the enclosed envelope, or by fax or by email.

YOUR PARTICIPATION IS GREATLY APPRECIATED!

If you have any questions or concerns about completing the questionnaire or about being in this study, please contact us in Edmonton at 780-488-9088, or toll free at 1-800-387-2514. You can also reach us by e-mail at Melita@accd.net.

We will be hosting FOCUS GROUPS, as well, and if you are interested in participating in one, please contact us.

Sincerely,

ACCD Project Team

1. Please check ALL that apply.
    - ☐ I am in full-time medical practice
    - ☐ I am in part-time medical practice
2. Which of these best describes you?
    - ☐ Family physician/general practitioner
    - ☐ Medical/surgical/laboratory specialist
    - ☐ Physician working exclusively in a non-clinical setting
    - ☐ Other, *please specify:*
3. For statistical purposes, what is your gender?
    - ☐ Male
    - ☐ Female
4. Where is your office located in Alberta? _____
5. How long has your office/clinic been open?

    _____
6. Check the category (ies) which best describe(s) the setting(s) where you work.
    - ☐ Private office/clinic
    - ☐ Community clinic/Community health centre
    - ☐ Free-standing walk-in clinic
    - ☐ Academic health sciences centre
    - ☐ Community hospital
    - ☐ Emergency department
    - ☐ Free-standing lab/diagnostic clinic
    - ☐ Other, please specify:
7. With respect to your MAIN patient care setting specified, describe the population PRIMARILY served by you in your practice.
    - ☐ Inner city
    - ☐ Urban/Suburban
    - ☐ Small town
    - ☐ Rural
    - ☐ Geographically isolated/Remote

- ☐ Other, please specify

8. Why did you consider establishing your practice at your current location?

- ☐ Location
- ☐ Affordability
- ☐ Wheelchair accessible
- ☐ Public transit route
- ☐ Other, please specify:

9. Please indicate with whom you regularly collaborate in providing patient care.

- ☐ Family physicians
- ☐ Psychiatric specialists
- ☐ Pediatric specialists
- ☐ Obstetrical/gynaecological specialists
- ☐ Internal specialists
- ☐ Surgical specialists
- ☐ Dieticians/nutritionists
- ☐ Occupational therapists
- ☐ Physiotherapists
- ☐ Mental health counsellors
- ☐ Social workers
- ☐ Speech-language pathologists
- ☐ Other

10. How many patients with disabilities do you have at your current practice?

- ☐ 1 to 5 patients
- ☐ 6 to 10 patients
- ☐ 11 to 20 patients
- ☐ more than 21 patients

11. Types of disabilities represented by your patients (check ALL that apply):

- ☐ Chronic medical disorders
- ☐ Cognitive disorders
- ☐ Intellectual disorders

- ☐ Mental health and substance abuse
- ☐ Physical impairment
- ☐ Sensory impairment

Questions	Yes	No	Not Sure
12. Are there clearly marked accessible parking stalls at your office?	☐	☐	☐
13. Is there a path of travel that does not require the use of stairs?	☐	☐	☐
14. If there are stairs, is there a ramp that allows easy access to the entrance?	☐	☐	☐
15. Are there clearly visible and easily understood signs to indicate the entrance?	☐	☐	☐
16. Is there a smooth surface transition from the parking to the entrance?	☐	☐	☐
17. Are there power door operators at the interior and exterior entrances of your office?	☐	☐	☐
18. Is there enough space for a wheelchair/scooter to use the entrance?	☐	☐	☐
19. Is the entrance door to your office easy to open (minimal strength required to open or close)	☐	☐	☐
20. Does the reception area have a lowered section of counter for people who cannot stand when speaking with the receptionist?	☐	☐	☐
21. Can objects protruding from the walls be easily detected by canes used by people with visual impairments?	☐	☐	☐
22. Are the hallways leading to the examining room wide enough for a wheelchair/scooter?	☐	☐	☐
23. Is the doorway into the examination room wide enough for a wheelchair/scooter?	☐	☐	☐
24. Are the door handles on the examination rooms lever type?	☐	☐	☐
25. Is there visible and easily understood directional signage?	☐	☐	☐
26. Is there strong colour contrast between the doors and walls?	☐	☐	☐

Questions	Yes	No	Not Sure
27. Are there enough chairs for use by people who cannot stand while waiting?	☐	☐	☐
28. Is there enough space in the waiting room for people in wheelchairs/scooters to manoeuvre/wait?	☐	☐	☐
29. Is there an accessible washroom with enough space for a wheelchair/scooter to fit and close the door?	☐	☐	☐
30. Is there enough space in the patient room for you and the staff to move around comfortably?	☐	☐	☐
31. Is there an adjustable examining table or a chair?	☐	☐	☐
32. Do the staff arrange to have a transfer team to assist people with physical impairments when moving from the mobility device/wheelchair/scooter to the table?	☐	☐	☐
33. Is there assistance throughout the procedures to move people with disabilities from one apparatus to another?	☐	☐	☐
34. Is there assistance for people with disabilities to undress/dress?	☐	☐	☐
35. Is there a scale with grab bars in your office for people who have difficulty standing?	☐	☐	☐
36. Is there a scale that allows people to be weighed while sitting in a wheelchair?	☐	☐	☐
37. Is there a scale that is attached to a sling lift so than an individual can be lifted and weighed?	☐	☐	☐
38. Is there a scale for people who weigh in excess of 350 lbs (158.75 kg)?	☐	☐	☐
39. Is there an amplified communication system or device with volume control at the reception desk?	☐	☐	☐
40. Is there a TTY phone at your office in order to contact patients with hearing impairments?	☐	☐	☐
41. Are the staff knowledgeable in using a TTY phone when contacting patients with hearing impairments?	☐	☐	☐
42. If needed, do the staff arrange for sign language interpreters in advance?	☐	☐	☐
43. Are alternate formats of communication provided?	☐	☐	☐
44. Is informational material available in various formats (Braille) at your office?	☐	☐	☐
45. Is there a washroom sign with Braille or raised letter instructions?	☐	☐	☐

Questions	Yes	No	Not Sure
46. Does your office accommodate various disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?	☐	☐	☐

47. When you prescribe a test like a mammogram or a CT scan, how do you assure that the location has accessible imaging devices? _____

48. My office has everything needed to provide patients with disabilities with complete medical care.

☐ Strongly Agree

☐ Agree

☐ Uncertain

☐ Disagree

☐ Strongly Disagree

49. Does your practice have a process to identify the needs of patients with disabilities?

☐ Yes

☐ No

50. If you answered *Yes* to Question 49, please explain your process._____

51. Do you have policies and procedures for managing patients with disabilities?

☐ Yes

☐ No

52. If you answered *Yes* to Question 51, please explain your policies and procedures in managing patients with disabilities._____

53. Do you offer training to your support staff in how to work and assist people with disabilities?

☐ Yes

☐ No

54. If you answered *Yes* to Question 53, please state examples of the training._____

55. Do you give people with disabilities written instructions on managing care at home?

☐ Yes

☐ No

56. If you answered *Yes* to Question 55, how much extra time is needed in order to accomplish this?_____

57. Do you routinely give patients a written list of all medications?

☐ Yes

- ☐ No

58. How would you rate your personal satisfaction with your practice?

- ☐ Very poor
- ☐ Poor
- ☐ Good
- ☐ Excellent

59. Your view on the current health system.

- ☐ Only minor changes are needed
- ☐ Fundamental changes are needed
- ☐ System needs to be completely rebuilt

60. What do you see as a major barrier to providing care to people with disabilities? _____

61. What would you like to see improved immediately regarding barrier-free access to medical clinics and diagnostic tests for people with disabilities? _____

People with Disabilities Survey

Dear Participant,

ACCD recently received a grant from the Alberta Human Rights and Multiculturalism Fund for a project entitled Barrier-Free Health and Medical Services in Alberta. This is not a government initiative but rather a project developed by ACCD in response to our members' personal experiences accessing health and medical services at doctors' offices throughout the province.

The Alberta Committee of Citizens with Disabilities is a consumer-directed provincial cross-disability organization that has worked since 1973 to promote full participation in society for Albertans with disabilities.

Over the years, we have heard numerous stories from people with disabilities about the barriers they face when visiting doctors' offices and accessing procedures in diagnostic labs. ACCD wishes to identify these barriers and work towards removing them by recommending changes so that people with disabilities can fully access necessary health and medical services.

ACCD has developed a survey to gather information on the experiences people with disabilities have when going to a doctor's office or diagnostic clinic.

The survey is ANONYMOUS! The information gathered is confidential and will not be shared with any other organization or regulatory body. There are no costs or risks to you for filling out the questionnaire.

Your answers will help us assess the needs of Albertans with disabilities when accessing health and medical services. We ask that you fill out the survey by June 30, 2010.

Please ANSWER ONLY THE QUESTIONS THAT RELATE TO YOU PERSONALLY! The questionnaire takes 15 20 minutes to complete. YOUR PARTICIPATION IS GREATLY APPRECIATED!

If you have questions or need assistance filling out this questionnaire, please contact us at 780-4889088 or 1-800-387-2514 or email Melita@accd.net.

We will be hosting FOCUS GROUPS, as well, and if you are interested in participating in one, please contact us.

Sincerely,

ACCD Project Team

General Information

1. What is your age?
    - 0-18
    - 19-30
    - 31-50
    - 51-70
    - 71 and over

2. What is your gender?
    - Male
    - Female

3. Where do you live in Alberta?

4. You live
    - Independently
    - Supportive Living
    - Lodge
    - Long-Term Care Facility
    - Other
    - Other (please specify)

5. What is/are your disability/disabilities?

6. You are
    - Employed
    - Unemployed
    - Unable to work because of a disability
    - Student
    - Retired

7. What is your total annual household income?
    - Less than $20,000
    - $20,000 to $39,999
    - $40,000 to $59,999
    - $60,000 to $79,999
    - $80,000 or more

8. Source of care support (please check ALL that apply)
    - My self
    - Family
    - Friends
    - Home care
    - Self-managed care
    - Supportive living
    - None required
    - Required, but not available

9. In general would you say your health is:
- Poor
- Fair
- Good
- Very Good
- Excellent

You, as the User of Services

10. I have a:
- Regular doctor (general practitioner) who is familiar with my disability
- Regular doctor (general practitioner) who is familiar with my disability but who is reluctant to help me have my needs met
- Regular doctor (general practitioner) who is not familiar with my disability
- Regular doctor (general practitioner) who is not familiar with my disability but is willing to work with me to help me have my needs met
- Problem finding a regular doctor (general practitioner)
- I use a medical center to access my regular doctor (general practitioner)

11. If you do have a regular doctor (general practitioner), how long has this person been your doctor?

12. Does this doctor handle most of your health care needs?
- Yes
- No

If you answered No, please explain who else handles your health care needs.

13. How often do you access medical and health services for REGULAR check ups?
- Once a week
- Once a month
- Once every 6 months
- Once a year
- Other

If you answered OTHER, please explain

14. How often do you access medical and health services for EMERGENCY services?
- Once a week
- Once a month
- Once every 6 months
- Once a year
- Other

If you answered OTHER, please explain

15. What diagnostic health services have you been referred to within the past year (please check ALL that apply)?
- Mammogram
- Blood test

- Bone scan
- PAP test
- X-ray
- MRI scan
- CT scan
- Prostate/bladder exam
- Colon exam
- None
- Other

If you answered OTHER, please explain

16. What diagnostic health services have you accessed within the past year?
- Mammogram
- Blood test
- Bone scan
- PAP test
- X-ray
- MRI scan
- CT scan
- Prostate/bladder exam
- Colon exam
- None
- Other

If you answered OTHER, please explain

Accessing Health and Medical Services in Alberta

17. What transportation do you use when accessing medical appointments and diagnostic tests?
- Private vehicle
- Specialized parallel transportation (Handibus)
- Taxi
- Public transit
- Other

18. If you answered Specialized Parallel Transportation, Taxi, or Public Transit for Question 17, how do you find using this transportation for accessing medical appointments?
- Very reliable
- Reliable
- Minor delays
- Not reliable

If you answered NOT RELIABLE please explain why_____

19. How many minutes does it usually take to get to your regular doctor's office?
- Less than 15 minutes
- 16 to 30 minutes

- 31 to 60 minutes
- More than 60 minutes

20. Is your doctor's clinic in a location where public transportation is available?
    - Yes
    - Somewhat
    - No

21. Please answer the following questions:

Questions	Yes	No	Not Sure	Not Applicable
Are there clearly marked accessible parking stalls at your doctor's office?	□	□	□	□
Is there a path of travel that does not require the use of stairs?	□	□	□	□
If there are stairs, is there a ramp that allows easy access to the entrance?	□	□	□	□
Is there clearly visible and easily understood signage to indicate entrance?	□	□	□	□
Is there a smooth surface transition from parking to entrance?	□	□	□	□
Are there power door operators at the interior and exterior entrances of your doctor's office?	□	□	□	□
Is there enough space for a wheelchair/scooter to use the entrance?	□	□	□	□
Is the entrance door to the doctor's office easy to open (minimal strength required to open or close)	□	□	□	□
Does the reception area have a lowered section of counter for people who cannot stand when speaking with the receptionist?	□	□	□	□
Can objects protruding from walls be easily detected by canes?	□	□	□	□
Are the hallways leading to the examining room wide enough for a wheelchair/scooter?	□	□	□	□
Is the doorway into the examination room, wide enough for a wheelchair/scooter?	□	□	□	□
Is the door handle on the examination rooms lever type?	□	□	□	□
Is there visible and easily understood directional signage?	□	□	□	□
Is there strong colour contrast on the doors and walls?	□	□	□	□
Are there enough chairs for use by people who cannot stand while waiting?	□	□	□	□
Is there enough space in the waiting room for people in wheelchairs to manoeuvre/wait?	□	□	□	□
Is there an accessible washroom with enough space for a wheelchair/scooter to fit and close the door?	□	□	□	□
Is there space in the waiting room's seating area to accommodate a wheelchair or scooter?	□	□	□	□
Is there enough space in the patient room for you and the staff to move around comfortably?	□	□	□	□

Is there an adjustable examining table or a chair?	□	□	□	□
Do the staff arrange to have a transfer team to assist you when moving from the mobility device/wheelchair/scooter to the table and assist you with positioning?	□	□	□	□
Is there assistance throughout the procedures to move from one apparatus to another?	□	□	□	□
Is there assistance to undress/dress?	□	□	□	□
Is there a scale with grabbers in your doctor's office for people who have difficulty standing?	□	□	□	□
Is there a scale that allows people to be weighed while sitting in a wheelchair?	□	□	□	□
Is there a scale that is attached to a sling lift so than an individual can be lifted and weighed?	□	□	□	□
Is there a scale for people who weigh in excess of 350lbs?	□	□	□	□
Is there an amplified communication system or device with volume control at the reception desk?	□	□	□	□
Is there a TTY for use to make phone calls?	□	□	□	□
Are the staff knowledgeable in using TTY when contacting you?	□	□	□	□
If needed, do the staff arrange for sign language interpreters in advance?	□	□	□	□
When making an appointment are alternate formats of communication provided?	□	□	□	□
Is the informational material available in various formats at your doctor's office?	□	□	□	□
Is there a washroom sign with Braille or raised letter instructions?	□	□	□	□

22. How would you rate the skills of the health care personnel assisting you with your disability-related needs during the exam?
    - Very poor
    - Poor
    - Fair
    - Good
    - Excellent

23. If your doctor does not have an appropriate scale to weigh you, where do you have your weight measured? Please explain.

24. Can you access services like mammograms, x-rays or CT scans?
    - Yes
    - No
    - Sometimes

If you answered NO or SOMETIMES, please explain why

25. Where do you access services like mammograms, x-rays or CT scans?
    - Hospital

- Diagnostic clinic
- Other

If you answered OTHER, please explain

26. Please tell us if you have had any issues when accessing medical devices for various exams that were prescribed by your doctor? _____

The Service

27. Please check the appropriate box for each question:

Question	Very Poor	Poor	Fair	Good	Very Good
The knowledge of the additional medical personnel (specialists, technicians, reception, nurses, and other doctors) of you as a patient.	□	□	□	□	□
The coordination between the additional medical personnel (specialists, technicians, reception, nurses, and other doctors) and your regular doctor	□	□	□	□	□
The personal manner (courtesy, carefulness, etc) of the health care professional at your doctor's office?	□	□	□	□	□

28. When you have a medical emergency and call the doctor's office for an appointment, how quickly do they usually see you?

- The same day
- The next day
- In 2 to 3 days
- In 4 to 5 days
- More than a week

29. How long do you wait to get an appointment if you do not have an emergency?

- The same day
- The next day
- In 2 to 3 days
- In a week
- In 2 to 3 weeks
- More than a month

30. Do you feel that the allocated time for an appointment is sufficient to meet your needs?

- Very sufficient
- Sufficient
- Somewhat sufficient
- Not sufficient

If you answered SOMEWHAT SUFFICIENT and NOT SUFFICIENT, please specify why_____

31. Does the doctor's office accommodate your disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?

- Yes
- No
- Sometimes

If answered NO or SOMETIMES, please specify why_____

32. Please answer the following questions:

Questions	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
My doctor sees my abilities rather than my disability	□	□	□	□	□
My doctor needs to be more thorough in treating and examining me	□	□	□	□	□
My doctor sees my disability as a cause for every symptom	□	□	□	□	□
My doctor listens to my concerns and symptoms	□	□	□	□	□
When I am receiving medical care, my doctor pays attention to my privacy	□	□	□	□	□
It is easy for me to get medical care	□	□	□	□	□
The medical personnel are good about explaining the reasons for medical tests	□	□	□	□	□
My doctor's office has everything needed to provide me with complete medical care	□	□	□	□	□
The doctors who treat me should be more respectful	□	□	□	□	□
During my medical visits, I am always allowed to say everything I think is important	□	□	□	□	□
When I go for medical care, they are careful to check everything when treating and examining me	□	□	□	□	□
It is hard for me to get medical care on short notice	□	□	□	□	□
The doctors who treat me have a genuine interest in me as a person	□	□	□	□	□
Sometimes doctors use medical terms without explaining what they mean	□	□	□	□	□
My doctor gives me advice and helps me to make decisions about my care	□	□	□	□	□
My doctor is supportive in completing forms on my behalf	□	□	□	□	□

33. How often do you leave your doctor's office with unanswered questions?

- Always
- Almost always
- A lot of the time
- Some of the time
- Almost never
- Never

34. Do you think that the health care system in Alberta needs:
- Complete overhaul
- Major reforms
- Minor reforms
- No reforms

35. What would you like to see improve immediately in your access to medical clinics and diagnostic tests? _____

The Need for Change

36. Please rate the following in importance for you:

Question	Very Important	Important	Neutral	Somewhat Important	Not Important
Accessible transportation	□	□	□	□	□
Reliable transportation	□	□	□	□	□
Parking stall for people with disabilities	□	□	□	□	□
Accessible entrances at medical clinics	□	□	□	□	□
Accessible medical exams	□	□	□	□	□
Availability of communication materials in alternative formats	□	□	□	□	□
Disability awareness	□	□	□	□	□
Medical services that are appropriate for my needs	□	□	□	□	□

37. Please tell us any additional information regarding your experiences when accessing health and medical services in Alberta.

38. If you would like us to contact you for further discussion, please provide your contact information, contact us at 1-800-387-2514, or email Melita@accd.net. We will be hosting FOCUS GROUPS as well, and if you are interested in participating in one, please contact us.

Appendix III: Health Professionals Survey Supplementary Tables

Table 1: Health Professionals Survey: Participant Location

Black Diamond	Calgary	Castor
Drumheller	Edmonton	Edson
Fairview	Fort Macleod	Fort McMurray
Fox Creek	Grande Cache	Lethbridge
Medicine Hat	Okotoks	Olds
Ponoka	Red Deer	Rocky Mountain House
Stand Off	Stony Plain	Sundre
Tofield	Vermillion	Vulcan

Table 2: Health Professionals Survey: Medical Practice

Please check ALL that apply:		
Answer Options	Response Percent	Response Count
I am in full-time medical practice	67.45%	29
I am in part-time medical practice	32.55%	14
	answered question	43
	skipped question	1

Table 3: Health Professionals Survey: Type of Health Professional

Which of these best describes you?		
Answer Options	Response Percent	Response Count
Family physician/General Practitioner	75.00%	33
Medical/Surgical/Laboratory specialist	11.37%	5
Physician working exclusively in a non-clinical setting	0.00%	0
Other	13.63%	6
	Answered question	44
	skipped question	0

Table 4: Health Professionals Survey: Gender

Gender		
Answer Options	Response Percent	Response Count
Male	54.55%	24
Female	45.45%	20
	answered question	44
	skipped question	**0**

Table 5: Health Professionals Survey: Setting(s) of practice (multiple answers per participant)

Check the category(ies) which best describe(s) the setting(s) where you work (ALL that apply)		
Answer Options	Response Percent	Response Count
Private office/clinic	70.45%	31
Community clinic/Community health centre	13.63%	6
Free-standing walk-in clinic	4.54%	2
Academic health sciences centre	9.09%	4
Community hospital	40.90%	18
Emergency department	36.36%	16
Free-standing lab/diagnostic clinic	0%	0
Other	4.54%	2
answered question		79
skipped question		0

Table 6: Health Professionals Survey: Population Served (multiple answers per participant)

With respect to your MAIN patient care setting specified, describe the population PRIMARILY served by you in your practice (ALL that apply).		
Answer Options	Response Percent	Response Count
Inner city	13.63%	6
Urban/Suburban	40.90%	18
Small town	34.09%	15
Rural	36.36%	16
Geographically isolated/Remote	2.27%	1
Other		
answered question		56
skipped question		0

Table 7: Health Professionals Survey: Reasons for establishment of practice at the current location

Why did you consider establishing your practice at your current location?		
Answer Options	Response Percent	Response Count
Location	67.50%	27
Affordability	20.00%	8
Wheelchair accessible	2.50%	1
Public transit route	10.00%	4
Other		
answered question		40
skipped question		4

Table 8: Health Professionals Survey: The collaborative process (multiple answers per participant)

Please indicate with whom you regularly collaborate in providing patient care.		
Answer Options	Response Percent	Response Count
Family physicians	88.63%	39
Psychiatric specialists	59.09%	26
Pediatric specialists	40.90%	18
Obstetrical/gynaecological specialists	59.09%	26
Internal specialists	65.90%	29
Surgical specialists	56.81%	25
Dieticians/nutritionists	59.09%	26
Occupational therapists	47.72%	21
Physiotherapists	70.45%	31
Mental health counsellors	72.72%	32
Social workers	54.54%	24
Speech-language pathologists	25.00%	11
Other	18.18%	8
	answered question	316
	skipped question	0

Table 9: Health Professionals Survey: Current number of patients with disabilities

How many patients with disabilities do you have at your current practice?		
Answer Options	Response Percent	Response Count
1 to 5 patients	11.63%	5
6 to 10 patients	9.30%	4
11 to 20 patients	6.98%	3
More than 21 patients	72.09%	31
	answered question	43
	skipped question	1

Table 10: Health Professionals Survey: Types of disabilities represented in the practice (multiple answers per participant)

Types of disabilities represented by your patients (check ALL that apply):		
Answer Options	Response Percent	Response Count
Chronic medical disorders	95.45%	42
Cognitive disorders	88.63%	39
Intellectual disorders	61.36%	27
Mental health and substance abuse	86.36%	38
Physical impairment	88.63%	39
Sensory impairment	63.63%	28
	answered question	213
	skipped question	0

Table 11: Health Professionals Survey: Physical accessibility - outside

Question	Yes	No	Not Sure	No Answer	Not Applicable
Are there clearly marked accessible parking stalls at your office?	41	2	0	1	0
	93.18%	4.55%	0.00%	2.27%	0.00%
Is there a path of travel that does not require the use of stairs?	38	6	0	0	0
	86.36%	13.64%	0.00%	0.00%	0.00%
If there are stairs, is there a ramp that allows easy access to the entrance?	19	3	1	12	9
	43.19%	6.82%	2.27%	27.27%	20.45%
Are there clearly visible and easily understood signs to indicate the entrance?	38	5	1	0	0
	86.36%	11.37%	2.27%	0.00%	0.00%
Is there a smooth surface transition from the parking to the entrance?	38	4	2	0	0
	86.36%	9.09%	4.55%	0.00%	0.00%
Are there power door operators at the interior and exterior entrances of your office?	21	23	0	0	0
	47.73%	52.27%	0.00%	0.00%	0.00%
Is there enough space for a wheelchair/scooter to use the entrance?	41	1	1	1	0
	93.19%	2.27%	2.27%	2.27%	0.00%

Table 12: Health Professionals Survey: Physical accessibility - inside

Question	Yes	No	Not Sure	No Answer
Is the entrance door to your office easy to open (minimal strength required to open or close)	33	8	3	0
	75.00%	18.18%	6.82%	0.00%
Does the reception area have a lowered section of counter for people who cannot stand when speaking with the receptionist?	11	30	1	2
	25.00%	68.18%	2.27%	4.55%
Can objects protruding from the walls be easily detected by canes used by people with visual impairments?	29	5	9	1
	65.91%	11.36%	20.46%	2.27%
Are the hallways leading to the examining room wide enough for a wheelchair/scooter?	42	1	1	0
	95.46%	2.27%	2.27%	0.00%
Is there visible and easily understood directional signage?	28	12	3	1
	63.64%	27.27%	6.82%	2.27%
Is there strong colour contrast between the doors and walls?	37	5	2	0
	84.09%	11.36%	4.55%	0.00%
Are there enough chairs for use by people who cannot stand while waiting?	42	1	1	0
	95.46%	2.27%	2.27%	0.00%
Is there enough space in the waiting room for people in wheelchairs/scooters to manoeuvre/wait?	40	2	2	0
	90.90%	4.55%	4.55%	0.00%
Is there an accessible washroom with enough space for a wheelchair/scooter to fit and close the door?	39	4	1	0
	88.64%	9.09%	2.27%	0.00%
Is there a washroom sign with Braille or raised letter instructions?	2	34	7	1
	4.55%	77.27%	15.91%	2.27%

Table 13: Health Professionals Survey: Examination room accessibility

Question	Yes	No	Not Sure	No Answer
Is the doorway into the examination room wide enough for a wheelchair/scooter?	39	3	2	0
	88.63%	6.82%	4.55%	0.00%
Are the door handles on the examination room's lever type?	18	23	3	0
	40.91%	52.27%	6.82%	0.00%
Is there enough space in the patient room for you and the staff to move around comfortably?	37	7	0	0
	84.09%	15.91%	0.00%	0.00%
Is there an adjustable examining table or a chair?	25	19	0	0
	56.82%	43.18%	0.00%	0.00%

Table 14: Health Professionals Survey: Equipment

Question	Yes	No	Not Sure	No Answer
Is there a scale with grab bars in your office for people who have difficulty standing?	4	39	1	0
	9.09%	88.64%	2.27%	0.00%
Is there a scale that allows people to be weighed while sitting in a wheelchair?	3	38	3	0
	6.82%	86.36%	6.82%	0.00%
Is there a scale that is attached to a sling lift so than an individual can be lifted and weighed?	4	39	1	0
	9.09%	88.64%	2.27%	0.00%
Is there a scale for people who weigh in excess of 350 lbs (158.75 kg)?	7	32	5	0
	15.91%	72.72%	11.37%	0.00%
Is there an amplified communication system or device with volume control at the reception desk?	3	34	5	2
	6.82%	77.27%	11.36%	4.55%
Is there a TTY phone at your office in order to contact patients with hearing impairments?	2	34	7	1
	4.55%	77.27%	15.91%	2.27%
Are the staff knowledgeable in using a TTY phone when contacting patients with hearing impairments?	2	28	12	2
	4.55%	63.63%	27.27%	4.55%

Table 15: Health Professionals Survey: Services

Question	Yes	No	Not Sure	No Answer
Do the staff arrange to have a transfer team to assist people with physical impairments when moving from the mobility device/wheelchair/scooter to the table?	15	28	1	0
	34.10%	63.63%	2.27%	0.00%
Is there assistance throughout procedures to move people with disabilities from one apparatus to another?	19	16	5	4
	43.19%	36.36%	11.36%	9.09%
Is there assistance for people with disabilities to undress/dress?	33	8	2	1
	75.00%	18.18%	4.55%	2.27%
If needed, do the staff arrange for sign language interpreters in advance?	6	29	5	4
	13.63%	65.91%	11.37%	9.09%
Are alternate formats of communication provided?	16	20	7	1
	36.37%	45.45%	15.91%	2.27%
Is informational material available in various formats (Braille) at your office?	1	36	6	1
	2.27%	81.83%	13.63%	2.27%
Does your office accommodate various disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?	23	16	3	2
	52.27%	36.36%	6.82%	4.55%

Table 16: Health Professionals Survey: My office has everything needed to provide patients with disabilities with complete medical care

My office has everything needed to provide patients with disabilities with complete medical care.		
Answer Options	Response Percent	Response Count
Yes	54.76%	23
No	38.09%	16
Not Sure	7.15%	3
answered question		42
skipped question		2

Table 17: Health Professionals Survey: My office has everything needed to provide patients with disabilities with complete medical care.

My office has everything needed to provide patients with disabilities with complete medical care.		
Answer Options	Response Percent	Response Count
Strongly Agree	4.54%	2
Agree	38.64%	17
Uncertain	25.00%	11
Disagree	27.27%	12
Strongly Disagree	4.55%	2
answered question		44
skipped question		0

Table 18: Health Professionals Survey: Does your practice have a process to identify the needs of patients with disabilities?

Does your practice have a process to identify the needs of patients with disabilities?		
Answer Options	Response Percent	Response Count
Yes	31.82%	14
No	68.18%	30
answered question		44
skipped question		0

Table 19: Health Professionals Survey: Policies and procedures for managing patients with disabilities

Do you have policies and procedures for managing patients with disabilities?		
Answer *Options*	Response Percent	Response Count
Yes	26.83%	11
No	73.17%	30
answered question		41
skipped question		3

Table 20: Health Professionals Survey: Training to your support staff in how to work and assist people with disabilities

Do you offer training to your support staff in how to work and assist people with disabilities?		
Answer Options	Response Percent	Response Count
Yes	24.33%	9
No	75.67%	28
answered question		37
skipped question		7

Table 21: Health Professionals Survey: Written instructions on managing care at home

Do you give people with disabilities written instructions on managing care at home?		
Answer Options	Response Percent	Response Count
Yes	53.48%	23
No	46.52%	20
answered question		43
skipped question		1

Table 22: Health Professionals Survey: Written list of all medications

Do you routinely give patients a written list of all medications?		
Answer Options	Response Percent	Response Count
Yes	39.54%	17
No	60.46%	26
answered question		43
skipped question		1

Table 23: Health Professionals Survey: Personal satisfaction with practice

How would your rate your personal satisfaction with your practice?		
Answer Options	Response Percent	Response Count
Very poor	0.00%	0
Poor	2.27%	1
Good	68.18%	30
Excellent	29.55%	13
answered question		44

Table 24: Health Professionals Survey: View on the current health system

Your view on the current health system		
Answer Options	Response Percent	Response Count
Only minor changes are needed	25.65%	10
Fundamental changes are needed	64.10%	25
System needs to be completely rebuilt	10.25%	4
answered question		39
skipped question		5

Appendix IV: People with Disabilities Survey Results Supplementary Tables

Table 25: People with Disabilities Survey: Age

What is your age?		
Answer Options	Response Percent	Response Count
0-18	4.15%	19
19-30	15.94%	73
31-50	37.77%	173
51-70	36.90%	169
71 and over	5.24%	24
	Answered question	458
	Skipped question	6

Table 26: People with Disabilities Survey: Age and Disability Category

Disability	0-18	19-30	31-50	51-70	71 and over	Skipped Question
Hearing	1	3	10	7	1	0
	0.22%	0.65%	2.18%	1.53%	0.22%	
Seeing	0	2	2	3	1	0
	0.00%	0.43%	0.43%	0.65%	0.22%	
Speech	0	0	1	0	0	0
	0.00%	0.00%	0.22%	0.00%	0.00%	
Pain	0	1	17	22	1	0
	0.00%	0.22%	3.71%	4.80%	0.22%	
Learning	1	14	2	3	0	0
	0.22%	3.06%	0.43%	0.65%	0.00%	
Mobility and Agility	8	20	67	63	12	1
	1.74%	4.37%	14.63%	13.76%	2.62%	
Memory	0	0	1	0	1	0
	0.00%	0.00%	0.22%	0.00%	0.22%	
Developmental	2	3	8	5	0	0
	0.43%	0.65%	1.75%	1.10%	0.00%	
Psychological (Mental)	1	5	5	3	0	0
	0.22%	1.10%	1.10%	0.65%	0.00%	
Multiple	5	10	31	25	2	0
	1.10%	2.18%	6.77%	5.46%	0.43%	
None	1	15	29	38	6	5
	0.22%	3.28%	6.33%	8.30%	1.31%	
				answered question		**458**
				skipped question		**6**

Table 27: People with Disabilities Survey: Gender

What is your gender?		
Answer Options	Response Percent	Response Count
Male	28.81%	132
Female	71.19%	326
	Answered question	458
	Skipped question	6

Table 28: People with Disabilities Survey: Gender and Disability Category

Disability	Male	Female	Skipped Question
Hearing	3	19	0
	0.65%	4.15%	
Seeing	4	4	0
	0.87%	0.87%	
Speech	0	1	0
	0.00%	0.22%	
Pain	6	35	0
	1.31%	7.64%	
Learning	6	13	1
	1.31%	2.84%	
Mobility and Agility	64	107	0
	13.97%	23.37%	
Memory	1	1	0
	0.22%	0.22%	
Developmental	7	11	0
	1.53%	2.40%	
Psychological (Mental)	2	12	0
	0.43%	2.62%	
Multiple	19	54	0
	4.15%	11.80%	
None	20	69	5
	4.37%	15.06%	
		answered question	458
		skipped question	6

Table 29: People with Disabilities Survey: Location of Participants

Airdrie	Drayton Valley	Irricana	Red Deer
Black Diamond	Drumheller	Lacombe	Sherwood Park
Botha	Duchess	Legal	Spruce Grove
Bow Island	Edmonton	Lethbridge	St Albert
Brooks	Edson	Lloydminster	Stettler
Calgary	Elk Point	Mayerthorpe	Stony Plain
Camrose	Fairview	Medicine Hat	Strathmore
Canmore	Fallis	Neerlandia	Sylvan Lake
Claresholm	Fort McMurray	Ohaton	Thorsby
Cochrane	Fort Saskatchewan	Okotoks	Tofield
Cold Lake	Grande Prairie	Onoway	Turner Valley
Coutts	High Prairie	Peace River	Vegreville
Crowsnest Pass	High River	Picture Butte	Vermilion
Devon	Innisfail	Ponoka	Wetaskiwin

Table 30: People with Disabilities Survey: Location of Participants and Disability-

Disability	Urban	Rural	Skipped Question
Hearing	19	2	1
	4.50%	0.47%	
Seeing	6	2	0
	1.42%	0.47%	
Speech	0	1	0
	0.00%	0.23%	
Pain	28	9	4
	6.64%	2.13%	
Learning	17	1	2
	4.06%	0.23%	
Mobility and Agility	128	37	6
	30.34%	8.77%	
Memory	2	0	0
	0.47%	0.00%	
Developmental	7	9	2
	1.66%	2.13%	
Psychological (Mental)	12	2	0
	2.84%	0.47%	
Multiple	57	12	4
	13.51%	2.84%	
None	50	21	23
	11.84%	4.98%	
		answered question	422
		skipped question	42

Table 31: People with Disabilities Survey: Living Settings

You live		
Answer Options	Response Percent	Response Count
Independently	76.11%	309
Supportive Living	10.10%	41
Lodge	0.74%	3
Long-Term Care Facility	0.98%	4
Other	12.07%	49
	answered question	406
	skipped question	58

Table 32: People with Disabilities Survey: Disability Type

Disability Category	Number of Survey Participants	Percentage of Survey Participants
Hearing	22	4.74%
Seeing	8	1.72%
Speech	1	0.22%
Pain	41	8.84%
Learning	20	4.31%
Mobility and Agility	171	36.85%
Memory	2	0.43%
Developmental	18	3.88%
Psychological (mental)	14	3.02%
Multiple	73	15.73%
None	94	20.26%
TOTAL	464	100.00%

Table 33: People with Disabilities Survey: Employment

You are		
Answer Options	Response Percent	Response Count
Employed	42.62%	185
Unemployed	9.91%	43
Unable to work because of a disability	25.11%	109
Student	11.52%	50
Retired	10.84%	47
	answered question	434
	skipped question	30

Table 34: People with Disabilities Survey: Household Income

What is your total annual household income?		
Answer Options	Response Percent	Response Count
Less than $20,000	31.11%	126
$20,000 to $39,999	17.28%	70
$40,000 to $59,999	14.32%	58
$60,000 to $79,999	14.32%	58
$80,000 or more	22.97%	93
	answered question	405
	skipped question	59

Table 35: People with Disabilities Survey: Household Income and Disability Category

Disability	Less than $20,000	$20,000 to $39,999	$40,000 to $59,999	$60,000 to $79,999	$80,000 or more	Skipped Question
Hearing	6	2	4	1	6	3
	1.48%	0.49%	0.98%	0.25%	1.48%	
Seeing	2	1	1	1	3	0
	0.49%	0.25%	0.25%	0.25%	0.74%	
Speech	1	0	0	0	0	0
	0.25%	0.00%	0.00%	0.00%	0.00%	
Pain	6	5	10	6	10	4
	1.48%	1.23%	2.47%	1.48%	2.47%	
Learning	12	2	3	0	0	3
	2.96%	0.49%	0.74%	0.00%	0.00%	
Mobility and Agility	39	25	18	36	39	14
	9.63%	6.18%	4.44%	8.88%	9.63%	
Memory	0	1	1	0	0	0
	0.00%	0.25%	0.25%	0.00%	0.00%	
Developmental	10	3	0	1	1	3
	2.47%	0.74%	0.00%	0.25%	0.25%	
Psychological (Mental)	5	6	0	0	2	1
	1.23%	1.48%	0.00%	0.00%	0.49%	
Multiple	34	10	7	6	10	6
	8.41%	2.47%	1.73%	1.48%	2.47%	
None	11	15	14	7	22	25
	2.71%	3.70%	3.46%	1.73%	5.44%	
					answered question	405
					skipped question	59

Table 36: People with Disabilities Survey: Source of Support (multiple responses per participant)

Source of care support (please check ALL that apply)		
Answer Options	Response Percent	Response Count
My self	63.17%	271
Family	58.04%	249
Friends	21.21%	91
Home care	9.79%	42
Self-managed care	17.01%	73
Supportive living	8.85%	38
None required	11.42%	49
Required, but not available	5.12%	22
answered question		429
skipped question		35

Table 37: People with Disabilities Survey: Source of Support and Disability Category(multiple answers per participant)

Disability	My self	Family	Friends	Home care	Self-managed care	Supportive living	None required	Required, but not available	Skipped Question
Hearing	14	10	2	1	0	1	5	0	0
	3.26%	2.33%	0.46%	0.23%	0.00%	0.23%	1.16%	0.00%	
Seeing	5	4	2	0	0	0	3	0	0
	1.16%	0.93%	0.46%	0.00%	0.00%	0.00%	0.69%	0.00%	
Speech	0	1	0	0	0	0	0	0	0
	0.00%	0.23%	0.00%	0.00%	0.00%	0.00%	0.00%	0.00%	
Pain	29	28	11	0	11	0	3	5	4
	6.75%	6.52%	2.56%	0.00%	2.56%	0.00%	0.69%	1.16%	
Learning	16	10	1	0	1	2	2	0	0
	3.72%	2.33%	0.23%	0.00%	0.23%	0.46%	0.46%	0.00%	
Mobility and Agility	107	102	33	29	42	14	8	2	4
	24.94%	23.77%	7.69%	6.75%	9.79%	3.26%	1.86%	0.46%	
Memory	0	1	0	0	0	0	0	1	0
	0.00%	0.23%	0.00%	0.00%	0.00%	0.00%	0.00%	0.23%	
Developmental	11	13	5	1	2	8	1	0	0
	2.56%	3.03%	1.16%	0.23%	0.46%	1.86%	0.23%	0.00%	
Psychological (Mental)	8	6	6	1	1	1	1	4	0
	1.86%	1.39%	1.39%	0.23%	0.23%	0.23%	0.23%	0.93%	
Multiple	43	45	17	6	12	7	4	8	3
	10.02%	10.48%	3.96%	1.39%	2.79%	1.63%	0.93%	1.86%	
None	39	29	14	4	4	5	22	2	24
	9.09%	6.75%	3.26%	0.93%	0.93%	1.16%	5.12%	0.46%	
								answered question	429
								skipped question	35

Table 38: People with Disabilities Survey: Health and Well-being

In general would you say your health is		
Answer Options	Response Percent	Response Count
Poor	11.3%	50
Fair	28.5%	126
Good	35.7%	158
Very Good	18.6%	82
Excellent	5.9%	26
	answered question	442
	skipped question	22

Table 39: People with Disabilities Survey: Regular Doctor

I have a:		
Answer Options	Response Percent	Response Count
Regular doctor (general practitioner) who is familiar with my disability	56.70%	220
Regular doctor (general practitioner) who is familiar with my disability but who is reluctant to help me have my needs met	6.95%	27
Regular doctor (general practitioner) who is not familiar with my disability	7.23%	28
Regular doctor (general practitioner) who is not familiar with my disability but is willing to work with me to help me have my needs met	15.98%	62
Problem finding a regular doctor (general practitioner)	5.67%	22
I use a medical center to access my regular doctor (general practitioner)	7.47%	29
	answered question	388
	skipped question	76

Table 40: People with Disabilities Survey: Regular Doctor and Disability Category

Disability	Regular doctor (general practitioner) who is familiar with my disability	Regular doctor (general practitioner) who is familiar with my disability but who is reluctant to help me have my needs met	Regular doctor (general practitioner) who is not familiar with my disability	Regular doctor (general practitioner) who is not familiar with my disability but is willing to work with me and help me have my needs met	Problem finding a regular doctor (general practitioner)	I use a medical center to access my regular doctor (general practitioner)	Skipped Question
Hearing	17	0	2	0	0	0	3
	4.38%	0.00%	0.52%	0.00%	0.00%	0.00%	
Seeing	5	0	1	0	0	0	2
	1.29%	0.00%	0.26%	0.00%	0.00%	0.00%	
Speech	0	1	0	0	0	0	0
	0.00%	0.26%	0.00%	0.00%	0.00%	0.00%	
Pain	11	8	3	7	3	2	7
	2.84%	2.06%	0.77%	1.80%	0.77%	0.52%	
Learning	8	0	4	1	4	1	2
	2.06%	0.00%	1.03%	0.26%	1.03%	0.26%	
Mobility and Agility	102	9	8	35	3	6	8
	26.29%	2.32%	2.06%	9.02%	0.77%	1.54%	
Memory	1	0	1	0	0	0	0
	0.26%	0.00%	0.26%	0.00%	0.00%	0.00%	
Developmental	12	1	0	1	1	2	1
	3.10%	0.26%	0.00%	0.26%	0.26%	0.52%	
Psychological (Mental)	6	0	3	3	1	0	1
	1.54%	0.00%	0.77%	0.77%	0.26%	0.00%	
Multiple	38	7	5	12	3	4	4
	9.79%	1.80%	1.29%	3.10%	0.77%	1.03%	
None	20	1	1	3	7	14	48
	5.15%	0.26%	0.26%	0.77%	1.80%	3.61%	
						answered question	388
						skipped question	76

Table 41: People with Disabilities Survey: Does this doctor handle most of your health care needs

Does this doctor handle most of your health care needs?		
Answer Options	Response Percent	Response Count
Yes	76.7%	297
No	23.3%	90
	answered question	387
	skipped question	77

Table 42: People with Disabilities Survey: How often do you access medical and health services for REGULAR checkups?

How often do you access medical and health services for REGULAR check ups?		
Answer Options	Response Percent	Response Count
Once a week	1.26%	5
Once a month	16.63%	66
Once every 6 months	27.96%	111
Once a year	30.98%	123
Other	23.17%	92
	answered question	397
	skipped question	67

Table 43: People with Disabilities Survey: How often do you access medical and health services for EMERGENCY services?

How often do you access medical and health services for EMERGENCY services?		
Answer Options	Response Percent	Response Count
Once a week	0.3%	1
Once a month	4.0%	15
Once every 6 months	12.6%	47
Once a year	26.1%	97
Other	57.0%	212
	answered question	372
	skipped question	92

Table 44: People with Disabilities Survey: What diagnostic health services have you been referred to within the past year (please check ALL that apply)?

What diagnostic health services have you been referred to within the past year (please check ALL that apply)?		
Answer Options	Response Percent	Response Count
Mammogram	28.6%	114
Blood test	79.9%	319
Bone scan	19.5%	78
PAP test	30.6%	122
X-ray	47.4%	189
MRI scan	25.1%	100
CT scan	20.8%	83
Prostate/bladder exam	16.8%	67
Colon exam	10.0%	40
None	7.5%	30
Other	20.1%	80
	answered question	399
	skipped question	65

Table 45: People with Disabilities Survey: What diagnostic health services have you accessed within the past year?

What diagnostic health services have you accessed within the past year?		
Answer Options	Response Percent	Response Count
Mammogram	25.2%	98
Blood test	77.9%	303
Bone scan	17.0%	66
PAP test	27.8%	108
X-ray	46.3%	180
MRI scan	23.9%	93
CT scan	18.8%	73
Prostate/bladder exam	16.5%	64
Colon exam	6.9%	27
None	9.0%	35
Other	18.0%	70
answered question		389
skipped question		75

Table 46: People with Disabilities Survey: Transportation used when accessing health and medical services (multiple answers per participant)

What transportation do you use when accessing medical appointments and diagnostic tests?		
Answer Options	Response Percent	Response Count
Private vehicle	77.7%	285
Specialized parallel transportation (Handibus)	15.3%	56
Taxi	3.8%	14
Public transit	15.0%	55
Other	11.4%	42
answered question		367
skipped question		97

Table 47: People with Disabilities Survey: If you answered Specialized Parallel Transportation, Taxi, or Public Transit for Question 17, how do you find using this transportation for accessing medical appointments?

If you answered Specialized Parallel Transportation, Taxi, or Public Transit for Question 17, how do you find using this transportation for accessing medical appointments?		
Answer Options	Response Percent	Response Count
Very reliable	19.3%	20
Reliable	22.1%	23
Minor delays	34.6%	36
Not reliable	24.0%	25
answered question		104
skipped question		360

Table 48: People with Disabilities Survey: How many minutes does it usually take to get to your regular doctor's office?

How many minutes does it usually take to get to your regular doctor's office?		
Answer Options	Response Percent	Response Count
Less than 15 minutes	37.4%	132
16 to 30 minutes	35.7%	126
31 to 60 minutes	20.1%	71
More than 60 minutes	6.8%	24
answered question		353
skipped question		111

Table 49: People with Disabilities Survey: Is your doctor's clinic in a location where public transportation is available?

Is your doctor's clinic in a location where public transportation is available?		
Answer Options	Response Percent	Response Count
Yes	62.3%	218
Somewhat	20.6%	72
No	17.1%	60
answered question		350
skipped question		114

Table 50: People with Disabilities Survey: Accessibility

Answer Options	**Yes**	**No**	**Not Sure**	**Not Applicable**	**Response Count**
Are there clearly marked accessible parking stalls at your doctor's office?	256	38	41	21	356
Is there a path of travel that does not require the use of stairs?	316	24	6	11	357
If there are stairs, is there a ramp that allows easy access to the entrance?	89	23	22	166	300
Is there clearly visible and easily understood signage to indicate entrance?	271	47	23	13	354
Is there a smooth surface transition from parking to entrance?	230	72	35	15	352
Are there power door operators at the interior and exterior entrances of your doctor’s office?	147	157	40	9	353
Is there enough space for a wheelchair/scooter to use the entrance?	222	44	66	19	351

Answer Options	Yes	No	Not Sure	Not Applicable	Response Count
Is the entrance door to the doctor's office easy to open (minimal strength required to open or close)	174	143	27	11	355
Does the reception area have a lowered section of counter for people who cannot stand when speaking with the receptionist?	67	248	28	11	354
Can objects protruding from walls be easily detected by canes?	99	58	139	52	348
Are the hallways leading to the examining room wide enough for a wheelchair/scooter?	238	35	64	15	352
Is the doorway into the examination room, wide enough for a wheelchair/scooter?	193	54	90	14	351
Is the door handle on the examination rooms lever type?	85	108	145	14	352
Is there visible and easily understood directional signage?	164	80	86	18	348
Is there strong colour contrast on the doors and walls?	85	130	116	15	346
Are there enough chairs for use by people who cannot stand while waiting?	288	46	11	7	352
Is there enough space in the waiting room for people in wheelchairs to manoeuvre/wait?	203	102	34	13	352
Is there an accessible washroom with enough space for a wheelchair/scooter to fit and close the door?	145	68	119	18	350
Is there space in the waiting room's seating area to accommodate a wheelchair or scooter?	210	89	37	15	351
Is there enough space in the patient room for you and the staff to move around comfortably?	198	123	23	11	355
Is there an adjustable examining table or a chair?	100	162	77	14	353
Do the staff arrange to have a transfer team to assist you when moving from the mobility device/wheelchair/scooter to the table and assist you with positioning?	41	90	92	124	347
Is there assistance throughout the procedures to move from one apparatus to another?	67	86	89	101	343
Is there assistance to undress/dress?	70	86	87	102	345

Answer Options	Yes	No	Not Sure	Not Applicable	Response Count
Is there a scale with grabbers in your doctor's office for people who have difficulty standing?	24	136	145	38	343
Is there a scale that allows people to be weighed while sitting in a wheelchair?	11	163	126	43	343
Is there a scale that is attached to a sling lift so than an individual can be lifted and weighed?	9	157	128	47	341
Is there a scale for people who weigh in excess of 350lbs?	11	92	180	62	345
Is there an amplified communication system or device with volume control at the reception desk?	21	118	153	50	342
Is there a TTY for use to make phone calls?	13	86	176	64	339
Are the staff knowledgeable in using TTY when contacting you?	12	40	186	97	335
If needed, do the staff arrange for sign language interpreters in advance?	9	37	187	100	333
When making an appointment are alternate formats of communication provided?	23	67	170	78	338
Is the informational material available in various formats at your doctor's office?	55	92	148	44	339
Is there a washroom sign with Braille or raised-letter instructions?	18	117	161	42	338
answered question					358
skipped question					106

Table 51: People with Disabilities Survey: How would you rate the skills of the health care personnel assisting you with your disability-related needs during the exam?

How would you rate the skills of the health care personnel assisting you with your disability-related needs during the exam?		
Answer Options	Response Percent	Response Count
Very poor	6.2%	20
Poor	11.4%	37
Fair	28.4%	92
Good	40.4%	131
Excellent	13.6%	44
answered question		324
skipped question		140

Table 52: People with Disabilities Survey: Can you access services like mammograms, x-rays or CT scans?

Can you access services like mammograms, x-rays or CT scans?		
Answer Options	Response Percent	Response Count
Yes	72.9%	250
No	5.8%	20
Sometimes	21.3%	73
answered question		343
skipped question		121

Table 53: People with Disabilities Survey: Where do you access services like mammograms, x-rays or CT scans? (multiple answers per participants)

Where do you access services like mammograms, x-rays or CT scans?		
Answer Options	Response Percent	Response Count
Hospital	51.8%	176
Diagnostic clinic	68.5%	233
Other	4.7%	16
answered question		340
skipped question		124

Table 54: People with Disabilities Survey: Courtesy and Knowledge

Please check the appropriate box for each question:						
Answer Options	Very Poor	Poor	Fair	Good	Very Good	Response Count
The knowledge of the additional medical personnel (specialists, technicians, reception, nurses, and other doctors) of you as a patient.	30	48	111	97	38	324
The coordination between the additional medical personnel (specialists, technicians, reception, nurses, and other doctors) and your regular doctor	29	51	98	106	36	320
The personal manner (courtesy, carefulness etc) of the health care professional at your doctor's office?	16	35	66	126	83	326
					answered question	329
					skipped question	135

Table 55: People with Disabilities Survey: When you have a medical emergency and call the doctor's office for an appointment, how quickly do they usually see you?

When you have a medical emergency and call the doctor's office for an appointment, how quickly do they usually see you?		
Answer Options	Response Percent	Response Count
The same day	32.1%	95
The next day	23.3%	69
In 2 to 3 days	18.9%	56
In 4 to 5 days	10.8%	32
More than a week	14.9%	44
answered question		296
skipped question		168

Table 56: People with Disabilities Survey: How long do you wait to get an appointment if you do not have an emergency?

How long do you wait to get an appointment if you do not have an emergency?		
Answer Options	Response Percent	Response Count
The same day	6.2%	20
The next day	7.1%	23
In 2 to 3 days	19.9%	64
In a week	32.5%	105
In 2 to 3 weeks	23.5%	76
More than a month	10.8%	35
answered question		323
skipped question		141

Table 57: People with Disabilities Survey: Do you feel that the allocated time for an appointment is sufficient to meet your needs?

Do you feel that the allocated time for an appointment is sufficient to meet your needs?		
Answer Options	Response Percent	Response Count
Very sufficient	18.2%	59
Sufficient	44.8%	145
Somewhat sufficient	19.4%	63
Not sufficient	17.6%	57
answered question		324
skipped question		140

Table 58: People with Disabilities Survey: Does the doctor's office accommodate your disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?

Does the doctor's office accommodate your disability needs (e.g. interpreter, alternative forms of communication, extra time for an appointment)?		
Answer Options	Response Percent	Response Count
Yes	58.9%	165
No	23.2%	65
Sometimes	17.9%	50
answered question		280
skipped question		184

Table 59: People with Disabilities Survey: Personal Perspectives

Answer Options	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	Response Count
My doctor sees my abilities rather than my disability	98	113	91	14	10	326
My doctor needs to be more thorough in treating and examining me	26	98	52	109	40	325
My doctor sees my disability as a cause for every symptom	16	35	79	126	66	322
My doctor listens to my concerns and symptoms	120	140	37	20	8	325
When I am receiving medical care, my doctor pays attention to my privacy	137	150	24	8	8	327
It is easy for me to get medical care	66	129	48	55	26	324

Answer Options	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree	Response Count
The medical personnel are good about explaining the reasons for medical tests	74	170	34	37	10	325
My doctor's office has everything needed to provide me with complete medical care	35	89	82	84	34	324
The doctors who treat me should be more respectful	29	42	44	132	69	316
During my medical visits, I am always allowed to say everything I think is important	102	138	23	42	18	323
When I go for medical care, they are careful to check everything when treating and examining me	62	110	65	69	14	320
It is hard for me to get medical care on short notice	56	88	50	97	29	320
The doctors who treat me have a genuine interest in me as a person	82	128	65	35	13	323
Sometimes doctors use medical terms without explaining what they mean	14	75	51	150	30	320
My doctor gives me advice and helps me to make decisions about my care	68	174	37	37	7	323
My doctor is supportive in completing forms on my behalf	101	141	47	22	13	324
answered question						331
skipped question						133

Table 60: People with Disabilities Survey: How often do you leave your doctor's office with unanswered questions?

How often do you leave your doctor's office with unanswered questions?		
Answer Options	Response Percent	Response Count
Always	2.5%	8
Almost always	6.1%	20
A lot of the time	7.4%	24
Some of the time	32.1%	105
Almost never	39.9%	130
Never	12.0%	39
answered question		326
skipped question		138

Table 61: People with Disabilities Survey: Do you think that the health care system in Alberta needs

Do you think that the health care system in Alberta needs		
Answer Options	Response Percent	Response Count
Complete overhaul	15.5%	50
Major reforms	49.7%	160
Minor reforms	33.6%	108
No reforms	1.2%	4
answered question		322
skipped question		142

Table 62: People with Disabilities Survey: The Need for Change

The Need for Change						
Answer Options	Very Important	Important	Neutral	Somewhat Important	Not Important	Response Count
Accessible transportation	154	76	41	18	32	321
Reliable transportation	192	63	36	11	17	319
Parking stall for people with disabilities	180	58	36	9	34	317
Accessible entrances at medical clinics	200	59	29	11	18	317
Accessible medical exams	213	64	22	7	11	317
Availability of communication materials in alternative formats	101	59	82	19	51	312
Disability awareness	194	86	27	6	2	315
Medical services that are appropriate for my needs	231	66	15	3	2	318
answered question						325
skipped question						139

Appendix V: Site Audit Request Letter

Dear Health Professional:

In February of 2010, the Alberta Committee of Citizens with Disabilities began working on a project to identify barriers to health and medical services in Alberta. ACCD's project team is currently working with professional associations and the health sector on an extensive literature review, community consultations, and audit-based case studies of health care facilities to determine best practices for reducing barriers to health and medical services.

ACCD is requesting permission to conduct an accessibility audit for the purposes of a case study in your health care facility. The audit, which will take about 45 minutes, can be conducted at a time that bests suits you, and the information gathered is **strictly confidential.** No identifying information will be cited, you will not be asked or expected to improve accessibility in your facility, and no personal information will be shared with any other organizations or government.

I will be contacting you shortly to arrange a suitable time. If you have any questions regarding this project, please contact me at 780-488-9088 or by email at travis@accd.net.

We appreciate your support.

Sincerely,

Travis Grant

Appendix VI: Barrier-Free Health and Medical Services in Alberta Annotated Bibliography

Access to Government Programs

Human Resources and Skills Development. (1999). *Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship.*

> The purpose of this document is to outline future directions the Government of Canada believes it must take to move towards full citizenship for all Canadians who are living with disabilities. These directions are consistent with the joint work begun with provinces and territories.

Link:http://www.servicecanada.gc.ca/eng/cs/sp/sdc/socpol/publications/reports/1999-000046/page08.shtml

Access to Health Care Services

Alberta Health and Wellness. (2004). *Improving Access to Health Services.*

> This document describes how wait lists are one of the primary concerns to Albertans and what can be done to eliminate this problem.

Link: http://www.health.alberta.ca/documents/Comparable-Improve-Access-2004.pdf

Alberta Health and Wellness. (2008). *Vision 2020: The Future of Health Care in Alberta.*

> VISION 2020 sets the course for a health system that is first and foremost geared toward the needs of the patient. Albertans want and deserve an excellent health-care system. They want a system that provides the care they need today and into the future and one that adapts to Albertans' changing needs, but will be there for them when they need it. They want a system that supports a high quality of life now and in the years to come. VISION 2020 identifies a path forward for Alberta's health system and describes how health care will be delivered in a strong, sustainable way by the year 2020. It builds on, and goes beyond, the studies and work done to date to improve access and quality – from the Mazankowski report in 2001, to a recent review of health service delivery. VISION 2020 provides direction on how to improve the delivery of services across the entire health system including public health, acute and continuing care, and delivery of pharmaceuticals, ambulance services, health system governance, and accountability.

Link: http://www.health.alberta.ca/documents/Vision-2020-Phase-1-2008.pdf

Alberta Health Services. (2009). *Strategic Direction 2009-2010: Defining Our Focus/Measuring Our Progress.*

> This plan describes our values, goals, focus and key priorities. These priorities address goals established by the Government of Alberta and are aligned with *Vision 2020*. This plan also incorporates feedback received through a consultation process. Input was received from a number of sources including physicians, staff, associations and foundations. The plan was endorsed by the Alberta Health Services Board on June 30, 2009.

Access, quality and sustainability are challenges facing health care systems across Canada and in most jurisdictions around the world. Meeting these challenges requires us to focus on the system as a whole, while addressing key priorities. This document outlines the approach that Alberta Health Services will take.

The Alberta Health Services strategic plan will guide our organization and initially be operationalized by implementation of key initiatives outlined in the subsequent pages. It will be refreshed every year. Everyone throughout the organization will contribute to achieving the priorities through portfolio specific action plans and be measured through accountability agreements.

Link: http://www.albertahealthservices.ca/files/org-strategic-direction.pdf

Department of Health. (2003). *Fair Access to Care Services - Guidance on Eligibility Criteria for Adult Social Care.*

This guidance provides councils with social services responsibilities (hereafter referred to as "councils") with a framework for determining eligibility for adult social care. It covers how councils should carry out assessments and reviews, and support individuals through these processes. Councils should ensure that they can provide or commission services to meet eligible needs, subject to their resources and, that within a council area, individuals in similar circumstances receive services capable of achieving broadly similar outcomes.

Link:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653

Drainoni, Mari-Lynn; et al. (2006). *Cross-disability Experiences of Barriers to Health-care Access: Consumer Perspectives.*

In this article, the results of a series of focus groups with people with disabilities are presented. Consumers were asked about a broad set of barriers, such as problems with communication, transportation, and insurance, as well as about barriers related to physical accessibility. We used the Institute of Medicine's framework to categorize barriers as either structural, financial, or personal/cultural. Our results suggest that individuals with disabilities experience multiple barriers to obtaining health care and that these barriers are more pronounced for some types of health care than others. In addition, regardless of disability type, consumers consistently spoke about similar barriers. The results underscore the importance of taking a broad perspective when making policy decisions and the need for continued change and improvement in this area.

Link: http://www.accessmylibrary.com/article-1G1-152195979/cross-disability-experiences-barriers.html

Devaney, J. et al. (2009). *Navigatinghealth care: Gateways to Cancer Screening*

This article is the first phase in the Gateways to Cancer Screening project - a user-driven participatory research project that examines barriers and facilitators to preventive cancer screening for women with physical mobility disabilities. Through a systematic review of the existing literature on this subject, we discover that, despite the fact that women with disabilities have the same biological risk of developing cancer as non-disabled women, women with mobility impairments face systemic, architectural, procedural and attitudinal barriers to preventive cancer screening. Our goals are to identify barriers and facilitators to screening, identify the gaps in the existing literature related to issues of diversity and

ultimately set the stage for disabled women to effect change through the telling of their own stories.

Link: http://www.informaworld.com/smpp/content~content=a915168538~db=all~jumptype=rss

Devaney, J. et al. (2009) *Gateways to Cancer Screening Project: Preliminary Findings.*

This report outlines the main activities and accomplishments of the Gateways to Cancer Screening Project. The project is based on the premise that women with physical mobility disabilities have faced significant barriers in accessing cancer screening. The Gateways project developed a series of 5 peer-led focus groups in the Greater Toronto Area where women with physical mobility disabilities came forward to describe their experiences with cancer screening and propose recommendations to facilitate positive change.

Link:
http://www.cilt.ca/Documents%20of%20the%20CILT%20Website/Report%20May%2023.pdf

Hansen-Turton, T. et al. (2007). *Convenient Care Clinics: The Future of Accessible Health Care.*

The need for accessible, affordable, quality health care in the United States has never been greater. In response to this need, convenient care clinics (CCC) are being launched across the country to help provide care to meet the basic health needs of the public. These health care clinics, based in retail stores and pharmacies, are staffed by nurse practitioners (NPs). CCCs have been called a "disruptive innovation" because they are consumer-driven and they serve as a response to many health care patients who are unhappy with the current conventional health care delivery system – a system that is challenged to provide access to basic health care services when people need it the most. CCCs have evolved at a time when our health care system is floundering, and the need for accessible, affordable health care is at its greatest. NPs, possessing advanced clinical skills and a strong desire to expand access to care, are identified as the ideal provider to be in this setting and deliver these needed services. Easily accessible and affordable, this health care model provides an entry point into the health care system for those who were previously restricted access. In CCCs, NPs will diagnose and treat common health problems, triage patients to the appropriate level of care, advocate for a medical home for all patients, and reduce unnecessary visits to Emergency Rooms and Urgent Care Clinics.

Link: http://www.acnpweb.org/files/public/CCAWhitePaperFINAL.pdf

Iezzoni, Lisa and O'Day, Bonnie. (2006). *More Than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities.*

The book covers disability and access to health care, health care experiences of people with disabilities, and improving their health care in the USA. The authors give invaluable insights, being researchers/doctors who have experienced disabilities and who have spent much time with people having disabilities. The work is well constructed, documented, written and accessible to everyone. To illustrate various problems, the authors use clear examples and figures plentifully, which are easier to understand than written descriptions of the issues. Pertinent statistics are provided to state different issues. The roles of the Americans with Disabilities Act, Medicare, Medicaid and private insurance schemes are well discussed.

Link: http://books.google.com/books?id=S6X0fsGu-n4C&printsec=frontcover&dq=More+Than+Ramps:+A+Guide+to+Improving+Health+Care+Quality+and+Access+for+People+with+Disabilities&source=bl&ots=ffha-

pEAsg&sig=8aQwVBxQGx2cC1D30rom9Mmf8Eo&hl=en&ei=HhpzS9HcCMf5nAfq2bidCw&sa=X&oi=book_result&ct=result&resnum=1&ved=0CAcQ6AEwAA#v=onepage&q=&f=false

Issaacson Kailes, J. (2008). *"G's": Getting Access to Health Care for People with Physical Disabilities.*

The following article highlights steps people with disabilities can take to increase chances of getting the health care that they need.

Link: http://www.cdihp.org/5%20Gs%20aug08.pdf

Issaacson Kailes, J. and Mac Donald, C. (2005). *Providing Information in Alternative Formats.*

This brief will assist you in providing alternative formats. It reviews communication needs of people with visual, hearing, learning, and cognitive disabilities; and explains how you plan, produce, and deliver alternate formatted material. This brief also contains sources (vendors) for the production of alternative formats.

Link: http://www.cdihp.org/briefs/brief6a-alt-formats.html

Issaacson Kailes, J. and MacDonald, C. (2005). *Tools for Decreasing Health Care Barriers.*

The article discusses the Americans with Disabilities Act (ADA) as a tool to raise the quality and the standard of care that people with disabilities receive.

Link: http://www.cdihp.org/briefs/brief-intro.html

Issaacson Kailes, J. and MacDonald, C. (2008). *Choosing and Negotiating an Accessible Facility Location.*

The major pieces of federal legislation governing equal access to health care services for individuals with disabilities are the Rehabilitation Act (Rehab Act) and the Americans with Disabilities Act (ADA). These laws constitute a national mandate prohibiting discrimination based on disability in the provision of goods and services available to the public.

Link: http://www.cdihp.org/briefs/2.%20Brief-Choosing%20Location-FINAL%20Edition%202_12.22.08.pdf

Issaacson Kailes, J. and MacDonald, C. (2008). *Improving Accessibility with Limited Resources.*

When funds are not available to remove all existing barriers, the Department of Justice (DOJ) recommends an order of priorities for barrier removal:

1. Provide access from public transportation, parking areas, sidewalks, and entrances to the public (e.g., installing an entrance ramp, widening entrances, and providing accessible parking spaces).
2. Provide access to those areas where goods and services are provided (e.g., adjusting the layout of display racks, clearing routes to exam rooms, rearranging tables, providing Braille and raised character signage, widening doors, providing visual alarms, and installing ramps).
3. Provide access to rest room facilities when they are open to the public (e.g., removal of obstructing furniture or vending machines, widening of doors,

installing of ramps, providing accessible signage, widening of toilet stalls, and installation of grab bars).

4. Take other measures to provide access to goods, services, or facilities.

Link: http://www.cdihp.org/briefs/3.%20Brief-Access%20Limited$-FINAL%20Edition%202_12.28.08.pdf

Issaacson Kailes, J. and MacDonald, C. (2009). *Health Care (Clinic/Out-patient) Facilities Access.*

> People with disabilities should be able to travel to a health care site, approach and enter and move around the building as conveniently as everyone else.

Link: http://www.cdihp.org/briefs/4.%20Brief-Health%20Care%20(outpatient_clincs)%20Facilites%20-%20FINAL%20Edition%202_1.5.09.pdf

Mudrick, N. and Yee, S. (2007). *Defining Programmatic Access to health care for People with Disabilities.*

> A growing number of publications document that people with disabilities experience barriers in the delivery of appropriate primary and preventive health care. The barriers to access that can be considered programmatic include aspects of how physician offices operate, the accessibility of the equipment utilized for medical examinations, the medical responses of doctors and nurses to patients with disabilities, and the absence of physician and allied health professional expertise regarding the provision of primary care to someone with a disability.

Link: http://www.dredf.org/healthcare/Healthcarepgmaccess.pdf

Richards, Elizabeth. (2007). *Hospital Quality Study in America: Annual Report Polls 5000 Hospitals based on Medicare Records*.

> This article comments on the annual Hospital Quality in America Study which was released in 2007 and showed a wide gap in the quality of care between the top performing hospitals and all other care providers. The study included evaluation of 18 procedures and conditions. 5000 hospitals across the US were studied over a two year period. Results were based on Medicare records from over 40 million hospitals. Researchers used the data to determine the best and worst regions and states in the country for hospital care.

Link: http://healthcare-research.suite101.com/article.cfm/best_places_for_good_hospital_care

Sofaer, S. and Carmel, M. (2000). *Coordination of Care for Persons with Disabilities Enrolled in Medicaid Managed Care: A Conceptual Framework to Guide the Development of Measures.*

> The purpose of this document is to present a conceptual framework to guide the development of measures of care coordination that would be both feasible to apply and meaningful in assessing the performance of Medicaid managed care organizations (MCOs) that enroll people with disabilities. Although there are no explicitly required care coordination systems now in place, some states are providing systems of coordination and doing it with existing resources. This document presents a structure for defining and measuring good care coordination for states that have systems and want to measure them, and for those who may wish to implement systems in the future.

Link: http://aspe.hhs.gov/daltcp/reports/carecoor.htm

The Center for Universal Design and The North Carolina Office on Disability and Health. *Removing Barriers to Health Care: A Guide for Health Professionals.*

> This document provides guidelines and recommendations to help health care professionals ensure equal use of the facility and services by all their patients. The information in this guide gives health care providers a better understanding of how to improve not only the physical environment, but also their personal interactions with patients with disabilities. There is also a review of some of the design standards established through state and federal laws, such as the Americans with Disabilities Act (ADA), that health care professionals need to know.

Link: http://www.fpg.unc.edu/~ncodh/RBar/index.htm

The Practice-based Research Network of the Family, Medicine Department of Université de Montréal. (2009). *Are Relational and Technical Quality of Care Related to One Another?*

> Few studies take into account simultaneously the relational and technical aspects of quality of care. A pilot study to explore the determinants of quality of care in patients followed for either HBP, Type II Diabetes and/or COPD in family medicine training settings.

Link: http://www.f2fe.com/CAHSPR/2009/docs/A6/a6a%20Marie-Dominique%20Beaulieu.pdf

Accessibility Guidelines

Americans with Disabilities Act. *Accessibility Guidelines for Buildings and Facilities.*

> This document contains scoping and technical requirements for accessibility to buildings and facilities by individuals with disabilities under the Americans with Disabilities Act of 1990. These scoping and technical requirements are to be applied during the design, construction, and alteration of buildings and facilities.

Link: http://www.access-board.gov/adaag/ADAAG.pdf

Bell, B. (2009). *Universal Design and ADA.*

> The combination of enforcing the law enacted in 1990 on both a federal and state level led to creating new building codes and local legislation. This momentum directly resulted in the creation of a Universal Design initiative, which enables millions of Americans to live more comfortable and accessible lives. In the course of growing the public's awareness of accessibility for a small portion of the population, a better lifestyle has evolved for all - and for younger generations this societal "attitude adjustment" is probably taken for granted.

Link: http://public-healthcare-issues.suite101.com/article.cfm/universal_design_and_ada

Jones, K. and Tamari, I. (1997*). Making Our Offices Universally Accessible: Guidelines for Physicians.*

> The purpose of this project was to develop specific recommendations to help physicians make their offices accessible to all patients and to provide some practical suggestions concerning how to do this.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1232828/pdf/cmaj_156_5_647.pdf

Accessible Health Facilities

Center for Disability Issues and the Health Professions. (2007). *Policy and Procedures: Accessible Medical Facility Series.*

> The purpose of this document is to establish written procedures (for all departments in medical clinics, doctors offices and other appropriate settings) for obtaining and documenting an accurate weight measurement for all patients; including those with physical disabilities and/or activity limitations which may include but not be limited to the inability to stand, balance, weakness, and spasticity.

Link: http://www.chcs.org/usr_doc/People_with_Disabilites_-_Sample_Policy_&_Procedure_Templates_for_Clinics_and_Doctors_Offices.pdf

Finch, Paul. (2005). *Doctors' Orders: health care Architecture, Too Often a Functionalist Response to Short-Term Budgeting, Should Increasingly Be Based on the Wealth of Evidence about How Patients Respond to Different Physical Environments.*

> What sort of hospitals do we want in the twenty-first century, how might they differ from those of the recent past, and why would we change them? In March 2002, AR carried an article on evidence-based design which showed that certain environments would help patients recover more quickly, using fewer drug treatments. That sort of research continues, and continues to confirm what every patient knows: that physical environment has an effect on the way you feel; and as every doctor knows, the way you feel has an effect on your state of both mind and health. The dilemma for designers, both generalists and specialists, is how to synthesise the increasing body of knowledge about the relationship between design and well-being with the requirements of those who commission hospitals. It is all very well saying that every patient should have their own room with their own nurse and (to exaggerate) their own personal physician on call twenty-four hours a day. Life is not like that. But how close would it be possible to come to the civilised environment for patient, staff and visitor without incurring costs disproportionate to the improvements achieved?

Link: http://findarticles.com/p/articles/mi_m3575/is_1299_217/ai_n13810224/

Radaj, D. (2009). *Creating an Age-less and Barrier-free Bathroom.*

> Great trends are occurring in bathrooms, such as incorporating more Universal Design elements, while making bathrooms aesthetically pleasing and *not* looking like hospital facilities. Since the population is aging, even if *you* aren't retiring soon, incorporating Universal Design features into a bathroom remodel will not only add value to your home, but will help ensure your age-less bathroom is ready if and when it may be needed. Of course, Universal Design features aren't only for the elderly but also for those who've been in an accident, suffer from arthritis or other disability.

Link: http://www.healthyhouseinstitute.com/a_1028-Creating_an_Age_less_and_Barrier_free_Bathroom

Rawlings, S. and White, D. (2005). *Beyond the Universal Patient Room.*

> The idea behind the original universal room concept was to allow patients to stay in a single location for the duration of their hospital stay, rather than moving them three to four times as their acuity level changed. The model, toured extensively at Celebration Health in Florida, provided rooms that were private and large enough to accommodate whatever level of care the patient required. Patient satisfaction, safety, and operational benefits were identified immediately, and the concept took hold. The universal room regenerated the need for a decentralized nursing model. This system, while still preferred by most nurses for its ability to deliver more personalized care, has its disadvantages. The need for teaming, "cross-pollination," and simple co-mingling of staff is critical in developing a supportive work environment. Purely decentralized models neglected this reality and tended to separate the staff. Newer models, referred to as "hybrid" or "decentralized teaming," modify these restrictions. For the best patient units today, not only are family amenities being planned, but also spaces for caregivers to relax, conduct conversations, and basically recharge. Architectural firm RTKL Associates, Inc., refers to these areas as "nursing rest stops" and considers them as important to the success of the unit design as any other part of the plan.

Link:[*http://www.healthcaredesignmagazine.com/ME2/Sites/dirmod.asp?sid=&nm=&type=Publishing&mod=Publications%3A%3AArticle&mid=8F3A7027421841978F18BE895F87F791&tier=4&id=62BADF96EC3F46FBB82B4F1ED94B93ED&SiteID=Main%20Si_e*](http://www.healthcaredesignmagazine.com/ME2/Sites/dirmod.asp?sid=&nm=&type=Publishing&mod=Publications%3A%3AArticle&mid=8F3A7027421841978F18BE895F87F791&tier=4&id=62BADF96EC3F46FBB82B4F1ED94B93ED&SiteID=Main%20Si_e)

The FPG Child Development Institute. *Removing Barriers to Health Care.*

> This booklet provides guidelines and recommendations to help health care professionals ensure equal use of the facility and services by all their patients. The information in this guide gives health care providers a better understanding of how to improve not only the physical environment, but also their personal interactions with patients with disabilities. There is also a review of some of the design standards established through state and federal laws, such as the Americans with Disabilities Act (ADA), that health care professionals need to know.

Link: [*http://www.fpg.unc.edu/~ncodh/pdfs/rbhealthcare.pdf*](http://www.fpg.unc.edu/~ncodh/pdfs/rbhealthcare.pdf)

The Government of Alberta. (2009). *Technical Design Requirements for Health Care Facilities.*

> The purpose of this document is to provide architects, engineers, health care providers, facility administrators and operators involved in designing health care facilities with a comprehensive set of guidelines. The guidelines are intended as a reference rather than detailed instruction and should be useful for planning new facilities, and renovating and operating existing facilities.

Link:[*http://www.infrastructure.alberta.ca/Content/docType486/Production/BlueBook_2009.pdf*](http://www.infrastructure.alberta.ca/Content/docType486/Production/BlueBook_2009.pdf)

Wells, Jon. *Efficient Office Design for a Successful Practice*

> This article will explain how design elements can optimize efficiency and patient care. Some suggestions are more applicable to those starting from scratch or making large-scale changes, but even if construction isn't on your agenda, these tips can help you improve your current setup.

Link: http://www.aafp.org/fpm/2007/0500/p46.html

Accessible Transportation

The Government of Alberta Interdepartmental Working Group on Accessible Transportation. (1999). *Checklists for Policy Makers and Planners.*

> The checklists outline key areas to consider when introducing a new program, or altering an existing service. These key areas are further developed into specific questions and formulae to address the realities of transportation demand associated with developing and delivering community based services across Alberta.

Link: http://www.transportation.alberta.ca/Content/docType55/Production/LITCChecklists.pdf

Act

Accessibility for Ontarians with Disabilities Act. (2007). Accessibility Standards for Customer Service.

> Recognizing the history of discrimination against persons with disabilities in Ontario, the purpose of this Act is to benefit all Ontarians by,
>
> (a) developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025; and
>
> (b) providing for the involvement of persons with disabilities, of the Government of Ontario and of representatives of industries and of various sectors of the economy in the development of the accessibility standards.

Link: http://www.e-laws.gov.on.ca/html/source/regs/english/2007/elaws_src_regs_r07429_e.htm

Alberta Human Rights Commission. (2009). *Alberta Human Rights Act.*

> The act describes that no person shall:
> (a) deny to any person or class of persons any goods, services, accommodation or facilities that are customarily available to the public, or
> (b) discriminate against any person or class of persons with respect to any goods, services, accommodation or facilities that are customarily available to the public, because of the race, religious beliefs, colour, gender, physical disability, mental disability, ancestry, place of origin, marital status, source of income, family status or sexual orientation of that person or class of persons or of any other person or class of persons.

Link:http://www.qp.alberta.ca/574.cfm?page=A25P5.cfm&leg_type=Acts&isbncln=9780779744060

The Government of Alberta. (2000). *Alberta Regulation 208/2000: Health Care Protection Regulation.*

> This Regulation lays down detailed provisions concerning, inter alia: the definition of major surgical services (Sec. 2) and minor surgical services (Sec. 3), the consultation of patients with regard to enhanced medical goods or services (Sec. 5), record keeping by surgical facilities (Sec. 9), private and semi-private accommodation at surgical facilities (Sec. 11), periodic reporting to health authorities of the provision of insured surgical services (Sec. 15), the submission to health authorities of annual performance reports by surgical facilities (Sec. 16), the reporting to health authorities by surgical facilities of mishaps (Sec. 17), the change in ownership of surgical facilities (Sec. 19), and the

composition of the Premier's Advisory Council on Health, appointed by the Lieutenant Governor in Council (Sec. 21). The following Schedules are appended: 1. Minor surgical procedures; and 2. Standard and enhanced medical goods and services.

Link:[*http://www.qp.alberta.ca/574.cfm?page=2000_208.cfm&leg_type=Regs&isbncln=9780779724994*](http://www.qp.alberta.ca/574.cfm?page=2000_208.cfm&leg_type=Regs&isbncln=9780779724994)

The Government of Alberta. (2000). *Health Care Protection Act.*

Alberta's *Health Care Protection Act* governs the provision of surgical services through non-hospital surgical facilities. Ministerial approval of a contract between the facility operator and a regional health authority is required to provide insured services. Ministerial designation of a non-hospital surgical facility and accreditation by the College of Physicians and Surgeons of Alberta are also required. According to the College, there are currently 58 non-hospital surgical facilities with accreditation status. Of these, 26 facilities have contracts with regional health authorities to provide insured services.

Link:[*http://www.qp.alberta.ca/574.cfm?page=H01.cfm&leg_type=Acts&isbncln=9780779724987*](http://www.qp.alberta.ca/574.cfm?page=H01.cfm&leg_type=Acts&isbncln=9780779724987)

Assistive Technology

Brady, R. et al. (2007). *Assistive Technology Curriculum Structure and Content in Professional Preparation Service Provider Training Programs.*

ASSISTIVE TECHNOLOGY (AT) and AT services that enable people with disabilities to participate in society are increasingly a part of service provider practice. Professional preparation programs in the United States structure their courses and practice experiences to prepare students to meet the credential requirements to enter their profession. It is not clear, however, how the professional preparation programs are meeting the challenge of preparing service providers such as those in occupational therapy (OT), physical therapy (PT), special education (SE), and speech language pathology (SLP) to competently provide AT services. This article reports on the AT/AT services component of a study that examined the curriculum structure and content in professional preparation service provider programs in the United States in the area of AT and telehealth, particularly as it relates to children and youth with disabilities and special health care needs.

Link:
http://www.questia.com/read/5035162560?title=Assistive%20Technology%20Curriculum%20Structure%20and%20Content%20in%20Professional%20Preparation%20Service%20Provider%20Training%20Programs

Department of Health. (2008). *Research and Development Work Relating to Assistive Technology 2007-2008.*

The report covers research and development work carried out by or on behalf of any government department in relation to equipment that might increase the range and independence of older and disabled people.

The report places such research in the context of the National Service Framework for Long-term conditions and the White Paper on Health and Social Care. The report describes the wide range of government-funded projects supporting the development, introduction and evaluation of assistive technology. Relevant projects funded by the EU are also listed.

Link:
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086061.pdf

Dethlefs, N. and Martin, B. (2006). *Japanese Technology Policy for Aged Care.*

> Aged care provision is a burning issue in Japan due to the country's unparalleled longevity and a fraying tradition of children caring for parents. Use of technology offers one approach to helping ease the increasing burden of aged care. Ways of using technology can be conveniently classified into three options. The first is to rely on well-tested technologies developed outside Japan. The second option is for significant Japanese investment in high-technology aged care supports, including robotics. The third option is for significant Japanese development in barrier-free technology, a low-technology direction. Articulating these options and spelling out their likely consequences helps to highlight some of the implicit value judgements involved in Japanese technology policy for aged care.

Link: http://www.uow.edu.au/~bmartin/pubs/06spp.html

Harris, F. and Sprigle, S. *Outcomes of an Assistive Technology Intervention among Wheeled Mobility Users.*

> This paper reports the outcomes of an assistive technology (AT) intervention among seating and mobility clients at an acute rehabilitation hospital between 2002 and 2004. Three instruments, OTFACT, PIADS, and the ATOM, were administered during baseline and assessments made at 1 and 12 months post-intervention. Results showed that the measures were not significantly correlated at baseline, post 1 and post 12 months, indicating the intervention had a dissimilar impact on their respective constructs. Results are discussed in terms of methodological implications for future outcomes studies.

Link: http://www.mobilityrerc.gatech.edu/publications/OutcomesAssistiveTech.pdf

Jacobs, P. et al. (2003). *Economic Evaluation for Assistive Technology Policy Decisions.*

> In order to assess AT policies, including whether AT use should be expanded and which technologies to focus on, policy makers will need to obtain more concrete information about economic and health outcomes. Economic evaluation analysis and health technology assessment (HTA) are two related areas that have been used to assess the results and appropriateness of a wide range of health interventions and programs. Relatively few researchers have completed economic evaluation studies of AT systems, however. This article presents an outline of these tools and suggests the degree to which they can be used to provide further information regarding AT use.

Link:
http://www.questia.com/read/5002017906?title=Economic%20Evaluation%20for%20Assistive%20Technology%20Policy%20Decisions

Lahm, E. and Sizemore, L. (2002). *Factors That Influence Assistive Technology Decision Making.*

> Assistive technology has reached a level of sophistication and affordability that makes it available to a wide range of people with disabilities. In an era of information technology, both individuals with disabilities and their families are becoming more insistent on assistive technology as an option to be considered for increasing independence. Even Congress recognized the importance of technology for those with disabilities as specified

in the 1997 reauthorization of the Individuals with Disabilities Education Act (PL 105-17). (Individuals with Disabilities Education Act Amendments, 1997). That law includes mandates that committees that plan Individualized Education Programs (IEPs) consider assistive technology for children who might require it in order to obtain an appropriate education (Proffit & Combs, 1998).

Link:
http://www.questia.com/read/5035110753?title=Factors%20That%20Influence%20Assistive%20Technology%20Decision%20Making

Lenker, J. and Jutai, J. (2002). *Assistive Technology Outcomes Research and Clinical Practice: What Role for ICF?*

Design of products and environments for people with disabilities falls along a continuum of research and practice areas for clinicians and engineers who work in the field of assistive technology (AT)(Vanderheiden, 1997). This continuum encompasses a range of devices and products that include: crutches, canes, walkers and wheelchairs that facilitate mobility; computer-based software and hardware that aid spoken and written communication; and relatively simple devices used for dressing, bathing, and eating (Cook & Hussey, 2002). Practitioners in the AT field include occupational and physical therapists, speech-language pathologists, special educators, rehabilitation engineers, prosthetists and orthotists, and information technologists.

Link: http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_6A_e.pdf

Winters, Jack. (2006). *Interface Technologies for Enhancing Universal Access Tele-Exercise.*

PowerPoint presentation regarding implementation of tele-health services.

Link: http://www.rectech.org/conference/presentations/V%20-%20Tele-exercise%20Panel/Winters.pdf

Zabala, J. (1995). *The SETT Framework: Critical Areas to Consider When Making Informed Assistive Technologies Decisions.*

As the language of the Individuals with Disabilities Education Act (IDEA, P.L. 101-476) regarding assistive technology becomes widely known, much attention is being focused on school districts and the procedures and practices which school personnel use in arriving at decisions regarding the provision of assistive technology devices and services. Which students need assistive technology? What kind of technology is needed? Who is involved in making these decisions? What sort of data should be gathered to aid in the decision-making process? Much discussion has been generated about each of these questions. Though there are few quick and easy answers to any of there questions, the first three are generally addressed in some way by a combination of federal law and best practices in fields related to assistive technology. The answer to the fourth question is evolving and is the subject of this discussion.

Link:
http://www.2learn.ca/advancingaccessibility/AThandouts/Scott%20Marfilius%20PDF%20and%20PPT%20Resources/SETTshortpaper.pdf

Business Plan

Alberta Seniors and Community Supports. (2009). *Business Plan 2009-2012.*

> This document describes the Business Plan for Alberta Seniors and Community supports and the strategic goals that are to be accomplished between 2009 and 2012.

Link: http://www.seniors.alberta.ca/publications/businessplan/

Consumer Involvement in Decision Making

Abelson, Julia and Gauvin, Francois-Pierre. (2009). *Assessing the Impacts of Public Engagement: Putting the Cart Before the Horse?*

> Review of published and grey literature about public engagement impacts.

Link: http://www.f2fe.com/CAHSPR/2009/docs/A5/a5c%20Julia%20Abelson.pdf

Crichton, Anne, et al. (1997). *Health Care: A Community Concern? Developments in the Organization of Canadian Health Services.*

> The origin of this book was a 1989 NHRDP grant to conduct a literature review on specific strategies for strengthening community health services. In the final product, this objective seems to have been largely abandoned. Instead, the book focuses on three themes: (i) the imperatives for health care reform, (ii) the welfare state as the context for reforms, and (iii) the rise and nature of community participation in health care policy and practice. The main thesis of this book is that current reforms of the health care system signal a shift from the welfare state, as the context within which access to health care services is guaranteed, to the welfare society, where the emphasis is on health outcomes and "stakeholder" participation in health policy formation and service delivery. These changes are argued to be the result of two developments. First, the need to control and reduce government deficits and debts, which gave rise to the need to increase the efficacy and efficiency of the health care system. Second, the emergence of the health promotion movement as an expression of a shift in the goals of health care policy from a focus on access to health care services to a focus on health status and outcomes. The shift toward the welfare society is presented as part of a move toward various corporatist arrangements that are currently deemed to be both more effective in achieving political consensus and more efficient in achieving redistributional objectives.

Link:http://www.questia.com/read/102576070?title=Health%20Care%3a%20A%20Community%20Concern%3f

MASS LBP. (2009). *Engaging with Impact: Targets and Indicators for Successful Community Engagement by Ontario's Local Health Integration* Networks, A Citizens' Report from Kingston, Richmond Hill and Thunder Bay.

> *Engaging with Impact: Targets and Indicators for Successful Community Engagement* by Ontario's LHINs focuses on the value of community engagement. Specifically, it deals with the challenge of evaluating engagement and proposes a series of recommendations and indicators that can be used to assess performance and develop a culture of engagement that will help to rewrite the relationship between health administrators and their public. Local Health Integration Networks were created in 2006 with an explicit mandate to engage stakeholders and their communities. More than this, the idea of engagement was

central to their rationale. Proponents of the LHIN system argued that regional planning authorities would be better positioned than ministry officials to assess and interpret local needs. LHINs could do this because they would be in closer contact with the communities they served and because of the strength and number of local relationships they could forge and sustain.

Many of Ontario's LHINs have spent their first three years demonstrating the feasibility and merit of this rationale. Using their own expertise and intuition and sometimes relying on simple trial and error, they are working to better engage stakeholders and members of the public and to connect their efforts to other planning and integration processes.

Link: http://www.masslbp.com/media/engagingreport.pdf

Perry, Rowney, Casebeer, et al. (2007). *Determinants of Stakeholder Preferences for Health Resource Allocation.*

The objective was to explore the effects of selected demographic, economic, political, historical, and psychosocial background variables on the health resource allocation preferences expressed by professional, management, governance, client, private and public stakeholder groups in the Calgary Health Region.

Link: http://www.f2fe.com/CAHSPR/2009/docs/A5/a5a%20Mary%20Perry.pdf

Consumer Satisfaction with Health Care Survey Results

The Government of Alberta. (2003). *Focus Alberta: Research Findings.*

Results from a survey conducted in 2003. The survey gathered information regarding issues that Albertans are facing. The most important issues were heath care, education, infrastructure and crime.

Link: http://www.alberta.ca/home/documents/FocusABPresentationAug2003.pdf

University of Alberta. (2004). *The 2004 Public Survey About Health and the Health System in Alberta.*

Since 1996, Alberta Health and Wellness has contracted the Population Research Laboratory (PRL) at the University of Alberta to conduct the annual survey of 4000 adult Albertans. The purpose of the surveys is to obtain the views of the public on the performance of the health system in Alberta. The 2004 survey questionnaire was administered to a stratified sample of Albertans in each of the province's nine health regions. The PRL's computer assisted telephone interviewing (CATI) system was used to conduct the survey which took place from February 10 to March 31, 2004. This report details the findings from the survey.

Link: http://www.health.alberta.ca/documents/Health-System-Survey-2004.pdf

Court Cases

Americans with Disabilities Act. (2003). *Disability Rights Council et al. v. Washington Hospital Center.*

This court case deals with people with disabilities not being placed in an accessible inpatient room; being examined on inaccessible equipment which required them to be lifted onto an examination table; having such lifting performed in an improper manner;

having to wait significantly longer than other patients for an outpatient exam because the examination room with an accessible table was occupied; not receiving adequate inpatient services required as a result of a disability, such as assistance with eating, drinking and having bowel movements; and not receiving accessible equipment needed as an inpatient, such as an accessible call buttons and telephones.

Link: http://www.ada.gov/whc.htm

Americans with Disabilities Act. (2006). *Olson, et al. v. Sutter Health.*

Sutter agreed to take important steps over the next 10 years to improve access in the areas of architectural barrier removal, installation and use of accessible medical equipment, provision of auxiliary aids and services to assist in communication with people with sensory disabilities, and enhanced staff training and policy development on disability issues.

Link: http://www.dralegal.org/downloads/cases/Sutter/Fact_sheet_final.doc

Tate, Karla. (2001). *Disability and Health Care: The Eldridge Case.*

The relationship between health and disability can be relatively simple, such as attending routine examinations, or it can prove to be more complex, such as providing access to medical services for *all* persons. Access is the foremost issue embodied in the 1997 Supreme Court of Canada case, *Eldridge* v. *British Columbia (Attorney General)*. This document will briefly explain the case and its implications on the delivery of social programs in the future.

Link: http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb012-e.htm

The Barrier Free Health Care Initiative. (2009). *Accessiblehealth care Legal Advocacy.*

This document summarizes various court cases that illustrate how legal advocacy can improve access to health care for people with disabilities.

Link: http://thebarrierfreehealthcareinitiative.org/?page_id=16

Defining Disability

Salvador-Carulla, L. and Gasca, V. (2010). *Defining disability, functioning, autonomy and dependency in person-centered medicine and integrated care.*

According to the integrative or holistic approach to health, medicine should not only be focused in disease and illness, but also on the consequences of disease and its contextual factors, as well as the positive aspects of health, such as adaptive functioning, protective factors, quality of life and the links of all these domains to care policy and planning.

Functioning and disability (D&F) are two related domains of a single health construct key to understand the relationship between the individual and the disease, where social support plays an effect modifier role. Therefore, D&F is regarded as a key domain in the recent models of diagnosis (i.e. person-centered medicine) and intervention (i.e. Integrated Care as a complex adaptive system) within the holistic paradigm.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2834916/?tool=pubmed

Demographic Information

Alberta Health Services. (2008). *Demographics: Demographic Information of Diverse Populations.*

> This document presents the demographic information of diverse populations in the City of Calgary, and when possible provincial (Alberta) and national (Canada) comparisons have also been made. Developing a demographic profile is important, for it assists in measuring the socioeconomic and health conditions of a population. The amount of demographic information available on each topic in this document varies. This variation is due to lack of information in some of the key priority areas. All efforts have been made to include the most recent information in the document.

Link: http://www.calgaryhealthregion.ca/programs/diversity/demographics/demographics_of_div_pop.pdf

Alberta Seniors and Community Supports. (2006). *A Profile of Albertans with Disabilities: a Compilation of Information from National Data Sources.*

> This report provides an overview of disability demographic research and serves as a resource where readers can find descriptive information, such as the average total income for an Alberta woman with disabilities, or how Alberta compares to Canada or the other provinces in terms of disability prevalence.

Link: http://www.assembly.ab.ca/lao/library/egovdocs/2006/als/164878.pdf

Statistics Canada. (2001). *A Profile of Disability in Canada, 2001.*

> This article is the first in a series of PALS data releases. It contains survey results on the prevalence, type and severity of disability by age and sex.

Link: http://www.rhdcc.gc.ca/eng/cs/sp/sdc/pkrf/publications/research/2001-000123/89-577-XIE01001.pdf

Design Guidelines

Brawely, Elizabeth. (2009). *Enriching lighting design*.

> Good lighting is perhaps the most important and least understood element in designing health care environments. Both physically and mentally challenged individuals become more vulnerable and dependent on their environment to compensate for sensory impairments, including dimming eyesight, which interferes to some degree with daily activities as well as social and leisure activities – the things that provide emotional and social well-being.

Link: http://iospress.metapress.com/content/t5151v545346x40l/fulltext.pdf

Disability Policies

Bridget Murray, K. (2004). *Do Not Disturb: "Vulnerable Populations" in Federal Government Policy Discourses and Practices.*

> This paper explores the emergence of "vulnerable populations" within federal government policy discourses, and considers the implications of this development for

governmental practices. The paper argues that rather than defining poverty as a product of broader social and economic forces, the new focus on vulnerable populations is inextricably bound to neoliberal sensibilities that seek to individualize a wide range of social ills, and to the notion that communities are the appropriate locales for responding to individuals unwilling or unable to meet their own basic human needs.

Link: http://www.questia.com/googleScholar.qst?docId=5008899671

Cameron, David. (2001). *Disability and Federalism: Comparing Different Approaches to Full Participation.*

All modern democratic states have fashioned policies and programs in response to the needs of persons with disabilities. These vary from nation to nation and in Disability and Federalism the authors examine the impact of the federal regimes of Australia, Belgium, Canada, Germany, and the United States on disability policy and programs and evaluate whether disablement - including its international, organizational, political, and attitudinal dimensions - has affected the operation of federalism in the five countries studied. The conclusion that emerges is that neither federalism nor the specific type of federal regime makes much difference to the philosophy of government, the values that underlie policy-making, or the general policy orientation to disabled people at any given historical moment. Individual federal realities, however, are at the heart of the formation of disability policy and the striking variations in program design and delivery that occur between states.

Link:http://books.google.ca/books?id=q5F8Oqks7oUC&dq=Disability+and+Federalism:+Comparing+Different+Approaches+to+Full+Participation&printsec=frontcover&source=bl&ots=vgsapfXSg2&sig=85UMk1JtdbnNFIJg1pRwvoxNZs0&hl=en&ei=nIoBS-arNM7ZnAeqz5Al&sa=X&oi=book_result&#v=onepage&q=&f=false

College of Physicians and Surgeons of Ontario. (2008). *Physicians and the Ontario Human Rights Code: Policy Statement #5-08.*

The goal of this policy is to help physicians understand the scope of their obligations under the *Code* and to set out the College's expectation that physicians will respect the fundamental rights of those who seek their medical services.

Link:
http://www.cpso.on.ca/uploadedFiles/downloads/cpsodocuments/policies/policies/human_rights.pdf

Grabois , E. and Nosek, M. (2001). *The Americans with Disabilities Act and Medical Providers: Ten Years after Passage of the Act.*

This article discusses the impact of the Americans With Disabilities Act (ADA) on health care providers, both those serving women in state and locally funded health care facilities, and those serving women in private offices. It begins with a review of literature since passage of the ADA in 1990, followed by a summary of a National Study of Women With Physical Disabilities that was done at the Center for Research on Women With Disabilities (CROWD) (Nosek, Howland, Rintala, Young, & Chanpong, 1997), exploring what participants said about their health care providers and the kind of medical care they have received. It also outlines another CROWD study of primary care physicians' offices (Grabois, Nosek, & Rossi, 1999). Last is a review of a physician survey by CROWD that analyzes what physicians say about caring for women with physical disabilities.

Link:
http://www.questia.com/read/5000949280?title=The%20Americans%20with%20Disabilities%

20Act%20and%20Medical%20Providers%3a%20Ten%20Years%20after%20Passage%20of%20the%20Act

Human Resources Development Canada. (1999). *Lessons Learned from Evaluation of Disability Policy and Programs.*

> This article discusses the impact of the Americans With Disabilities Act (ADA) on health care providers, both those serving women in state and locally funded health care facilities, and those serving women in private offices. It begins with a review of literature since passage of the ADA in 1990, followed by a summary of a National Study of Women With Physical Disabilities that was done at the Center for Research on Women With Disabilities (CROWD) (Nosek, Howland, Rintala, Young, & Chanpong, 1997), exploring what participants said about their health care providers and the kind of medical care they have received. It also outlines another CROWD study of primary care physicians' offices (Grabois, Nosek, & Rossi, 1999). Last is a review of a physician survey by CROWD that analyzes what physicians say about caring for women with physical disabilities.

Link: http://www.hrsdc.gc.ca/eng/cs/sp/edd/reports/1999-000363/dpptr.pdf

Jongbloed, Lyn. (2003). *Disability Policy in Canada: An Overview. Journal of Disability*.

> Over the last century there has been a shift from conceptualizing disability as a challenge to law and order, to viewing disability as a medical and/or economic deficit and then as a sociopolitical issue. In Canada, these changing conceptualizations of disability have been reflected in the development of disability policies, which form part of general Canadian social policies. Each model of disability captures a particular aspect of disability and focuses on particular goals, and each depicts a different account of what society owes people with disabilities. However, the lack of linkages between the models and their conceptual bases means that no one model can be used to guide disability policy development. Decision making about the goals of disability policy and the rights of people with disabilities requires the development of a normative foundation.

Link:
http://www.questia.com/read/5001705967?title=Disability%20Policy%20in%20Canada%3a%20An%20Overview

Martin, M. and Nordal, C. (2008). *A Visit Down Under: Our Journey to Improve Canada's health care System.*

> This article discusses the impact of the Americans With Disabilities Act (ADA) on health care providers, both those serving women in state and locally funded health care facilities, and those serving women in private offices. It begins with a review of literature since passage of the ADA in 1990, followed by a summary of a National Study of Women With Physical Disabilities that was done at the Center for Research on Women With Disabilities (CROWD) (Nosek, Howland, Rintala, Young, & Chanpong, 1997), exploring what participants said about their health care providers and the kind of medical care they have received. It also outlines another CROWD study of primary care physicians' offices (Grabois, Nosek, & Rossi, 1999). Last is a review of a physician survey by CROWD that analyzes what physicians say about caring for women with physical disabilities.

Link: http://www.caho-hospitals.com/docs/AustraliaArticle_HQ_.pdf

O'Day, B. and Goldstein, M. (2005). *Advocacy Issues and Strategies for the 21st Century: Key Informant Interviews.*

> The authors conducted key informant interviews with 16 disability advocacy and research leaders; half of the interviews were with leaders in shaping national disability policy during and after passage of the Americans with Disabilities Act of 1990, and half were with state and local leaders representing constituencies who had not had a visible presence at the national level. During audiotaped telephone interviews, we asked the informants to identify the top 5 advocacy priorities for the next 10 years, as well as what strategies they thought could advance the disability advocacy agenda. Two overarching themes emerged: the impact of poverty among people with disabilities and the connections among various advocacy issues. The authors discuss the 5 issues most often cited by the participants, as well as issues particular to various constituencies, and draw conclusions about what strategies would advance the disability agenda.

Link:
http://www.questia.com/read/5009049335?title=Advocacy%20Issues%20and%20Strategies%20for%20the%2021st%20Century%3a%20Key%20Informant%20Interviews

Ontario Human Rights Commission. (2000). *Submission of the Ontario Human Rights Commission to the College of Physicians and Surgeons of Ontario Regarding the draft policy, "Physicians and the Ontario Human Rights Code."*

> This document presents the submission of the Ontario Human Rights Commission (the "Commission in response to the College's draft policy, "Physicians and the Ontario *Human Rights Code*" (the "draft policy").

Link: http://www.ohrc.on.ca/en/resources/submissions/physur?page=suben-Contents.html

Ontario Human Rights Commission. (2009). *Policy and Guidelines on Disability and the Duty to Accommodate.*

> In 1989, the OHRC published its *Guidelines on Assessing Accommodation Requirements for Persons with Disabilities*. These Guidelines were introduced after extensive consultations with stakeholders, and created for the first time a standard for the interpretation of "undue hardship." The Guidelines were cited before tribunals and the courts, and were an important interpretative tool. Since that time, there have been several important legal decisions, notably from the Supreme Court of Canada, with respect to the ground of disability and the duty to accommodate. These decisions have assisted the OHRC in its evolving understanding of equality for persons with disabilities. Significantly, the Supreme Court has noted the need to adapt society so that its structures and attitudes include persons with disabilities. This requires a shift in our approach to the entire area, one that affirms the centrality of human dignity in achieving equality.

Link: http://www.ohrc.on.ca/en/resources/Policies/PolicyDisAccom2/pdf

Putnam, M. (2005). *Developing a Framework for Political Disability Identity.*

> Empirical analysis of disability identity has great potential to improve understanding of the role of disability status in identity politics. Despite ongoing discussions of the relevance of disability identity in the disability rights movement and political actions related to disability, there is limited research into its nature and its underlying psychological, social, and political constructs. This may in part be caused by the lack of a theoretical model to guide analysis. This article proposes a conceptual framework to

guide empirical analysis of disability identity, outlining six potential construct domains and their subdomains based on a review of scholarly discussions and empirical research.

Link:
http://www.questia.com/read/5012409037?title=Developing%20a%20Framework%20for%20Political%20Disability%20Identity

Health Care Disparities

Agency for health care Research and Quality. (2008). *National health care Disparities Report.*

Examining health care disparities is an integral part of improving health care quality. Health care disparities are the differences or gaps in care experienced by one population compared with another population. As the National health care Quality Report (NHQR) shows, Americans too often do not receive care that they need or they receive care that causes harm. The National health care Disparities Report (NHDR) shows that moreover, some Americans receive even worse care than other Americans. The quality of health care is different for different people. Within the scope of health care delivery, these disparities are due to differences in access to care, provider biases, poor provider-patient communication, poor health literacy, and other factors.

The NHDR uses the same 220 measures used in the NHQR categorized across four dimensions of quality: effectiveness, patient safety, timeliness, and patient centeredness. This year's report focuses on the state of health care disparities for a group of 45 core measures that represent the most important and scientifically credible measures of health care quality for the Nation, as selected by the Department of Health and Human Services (HHS) Interagency Work Group. By focusing on core measures, the 2008 report provides a more readily understandable summary and explanation of the key results derived from the data. While the measures selected for inclusion in the NHDR are derived from the most current scientific knowledge, this knowledge base is not evenly distributed across the dimensions of health care quality, nor across racial, ethnic, and other priority populations. The analysis in the following pages centers on measures for which data are available and that fit within the framework provided by the Institute of Medicine.

Link: http://www.ahrq.gov/qual/nhdr08/nhdr08.pdf

Canadian Institute for Health Information. (2006). *Waiting for Health Care in Canada: What We Know and What We Don't Know.*

Chapter 1 addresses these issues. It tracks progress on understanding wait times across Canada. The chapter profiles a sample of the work underway, both within and outside of government. Drawing on results from a symposium on wait times measurement held in the fall of 2005, it also highlights shared underlying challenges in measuring and understanding wait times. The rest of the report explores what we know and do not know about wait times across the spectrum of care. It highlights findings from a range of surveys, provincial wait times data and other sources. Given the patchwork of information available, our intent is not to be comprehensive. Instead, our aim is to provide useful insights and a starting point for collective efforts to understand and reduce wait times. If you are interested in knowing more about a particular area, we have provided references to detailed documents or data sources where possible.

Link: http://secure.cihi.ca/cihiweb/products/WaitTimesReport_06_e.pdf

Lasser, K. et al. (2006). *Access to Care, Health Status, and Health Disparities in the United States and Canada: Results of a Cross-National Based Survey.*

> Comparisons of access to dental care in the 2 countries are of interest, given that neither country has universal dental coverage. Unlike physician services in Canada, which are fully insured in every province, dental coverage varies from province to province. In Canada, income disparities were much more pronounced for dental care than for medical care and were of a similar magnitude to the US disparities.

Link: http://www.medscape.com/viewarticle/536459

Parish, S. and Huh, J. (2006). *Health Care for Women with Disabilities: Population-Based Evidence of Disparities.*

> These findings suggest some troubling health care disparities exist between disabled and nondisabled women. Contrary to established trends in the general population, potential health care access for women with disabilities does not necessarily translate into receipt of care when it is needed. Social workers and advocates, both within and outside of health care settings, have unique and important opportunities to address these disparities through patient education, linkage to services, needs assessment, and policy development. Meeting the health care needs of women with disabilities is vitally important because these women are at greater risk of developing secondary conditions if their care needs are unmet.

Link:
http://www.questia.com/read/5013997991?title=Health%20Care%20for%20Women%20with%20Disabilities%3a%20Population-Based%20Evidence%20of%20Disparities

Torres, Tan et al. (2008). *Burden of Illness: Health Needs Assessment.*

> It is difficult to decide because the choices are limited to the technologies being considered, and the needs are vaguely described (i.e. a "worried" district doctor, "recommended" by a newly trained radiologist). To avoid being placed in such a difficult situation, one should pro-actively and regularly do a needs assessment. These needs can be prioritised based on burden of disease, availability of cost-effective technology and values or preferences of the community. A rational and responsive technology acquisition and implementation program can then be subsequently drafted.

Link:
http://www.intermed.med.uottawa.ca/research/globalhealth/whocc/projects/eo_toolkit/download/EOT_Burden_of_Illness.pdf

Health Care Expenditures

Canadian Institute for Health Information. (2002). *Public Health and Administration in National Health Expenditures: Feasibility Study.*

> This report discusses the results of a CIHI Roadmap project to examine the National Health Expenditures (NHEX) category of Public Health and Administrative Costs to determine the feasibility of separating public health expenditures from administrative cost estimates. Provincial and territorial estimates were revised back to 1989–1990 to separate public health and administration. Factors influencing the variability of provincial estimates were identified and recommendations to achieve greater consistency were developed. Differences in the way specific expenditures are reported in provincial public accounts are responsible for much of the variability and will continue to pose challenges

in classifying expenditures for NHEX. The report also recommends definitions for government administrative costs and prepayment administration that will result in more consistent classifications and resolve ambiguities that presently exist in classifying the administrative costs associated with delivering specific service programs.

Link: http://secure.cihi.ca/cihiweb/en/downloads/spend_PublicHealthNHEX_e.pdf

Health Care Models

Harper, K et al. (2006). *Low Vision Service Models in Alberta: Innovation, Collaboration, and Future Opportunities.*

As Alberta's population ages over the next 20 years, the number of older adults experiencing age-related blindness or vision loss is likely to at least double. To prevent a crisis in low vision service provision, we need to build upon, and extend, existing partnerships between the CNIB and ophthalmologists, optometrists, government policy makers, and other service providers. Future service models for low vision rehabilitation should also emphasize interventions such as counselling and peer support that enhance quality of life. With thoughtful planning, adequate funding, and involvement of all stakeholders, Alberta has the potential to become a world leader in the field of low vision treatment and rehabilitation.

Link: http://article.pubs.nrc-cnrc.gc.ca/RPAS/rpv?hm=HInit&journal=cjo&volume=41&afpf=i06-028.pdf

Louise Lapointe, Marie. (2006). *Services Available to Sight-Impaired and Legally Blind Patients in Ontario: the Ontario Model.*

The Participation and Activity Limitation Survey undertaken by Statistics Canada in 2001 identified 635 000 Canadians who have a seeing disability. By 2015 these numbers are expected to double, with the largest group of patients residing in Ontario, the province with the largest population. Ontario has a long established history of vision rehabilitation, but recent demographic changes and an ever-increasing older population have made the planning of vision rehabilitation services in Ontario (as in the rest of Canada) even more urgent. The intent of this paper is to present the variety of services currently available to the visually impaired in Ontario.

Link: http://article.pubs.nrc-cnrc.gc.ca/RPAS/rpv?hm=HInit&journal=cjo&volume=41&afpf=i06-023.pdf

Health Care Reforms

Acquilano, Nelson. (2009). *Health Care Reform: Essential Steps for Success.*

This article describes the health care system in the United States and the author makes various recommendations of how the health care system can be fixed. It is often characterized as a fragmented and haphazard system, inefficient, too expensive, and one which rewards insurance providers for denial of necessary coverage. Data released by the Census Bureau shows that the number of uninsured Americans stood at a record 46.6 million in 2005 - 15.9 percent of Americans lack health coverage. Tens of millions more find that their coverage is incomplete or denied and insufficient to the need. A price tag of one trillion dollars has been suggested to pay for the overhaul of the American system of health care in the present reform proposals. Many fear that the politics involved will create even greater fragmentation rather than fix a broken system. The Health Care

industry is currently guided not by consumer needs but by profit, lobbying and politics. Removing these variables and taking appropriate action steps on behalf of the needs of citizens is paramount for the long term success of any significant health care reform plan. The Health Care industry is currently guided not by consumer needs but by profit, lobbying and politics. Removing these variables and taking appropriate action steps on behalf of the needs of citizens is paramount for the long term success of any significant health care reform plan.

Link: http://public-healthcare-issues.suite101.com/article.cfm/health_care_reform_essential_steps_for_success

Armitage, G. et al. (2009). *Health Systems Integration: State of the Evidence.*

Integrated health systems are considered a solution to the challenge of maintaining the accessibility and integrity of health care in numerous jurisdictions worldwide. However, decision makers in a Canadian health region indicated they were challenged to find evidence-based information to assist with the planning and implementation of integrated health care systems.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707589/pdf/ijic2009-200982.pdf

Canadian Institute for Health Information. (2001). *Conceptual Health Data Model v2.3.*

The Conceptual Health Data Model project provides an overview of the essential foundations of data to be captured that can then be transformed into meaningful information to support the many different uses across the health system. Consistent data capture and systematic information transformation processes can result in more effective evidence being available to support health system management purposes. More importantly, value-added information can be supplied back to the clinician at the point of care, not only improving the clinician's ability to deliver quality health care but also providing an incentive to the clinician to capture the highest quality data as a by-product of providing first quality care.

Link: http://secure.cihi.ca/cihiweb/en/downloads/infostand_chdm_e_CHDMv2_31.pdf

Chapman, Audrey (ed). (1994). *Health Care Reform: A Human Rights Approach.*

Arguing that health care should be a human right rather than a commodity, the contributors to this volume call for a new social covenant establishing a right to a standard of health care consistent with society's level of resources. By linking rights with limits, they present a framework for seeking national consensus on a cost-conscious standard.

Link:http://www.questia.com/read/99219813?title=Health%20Care%20Reform%3a%20A%20Human%20Rights%20Approach

Donabedian, Avedis. (2005). *Evaluating the Quality of Medical Care.*

This paper is an attempt to describe and evaluate current methods for assessing the quality of medical care and to suggest some directions for further study. It is concerned with methods rather than findings, and with an evaluation of methodology in general, rather than a detailed critique of methods in specific studies.

Link: www.milbank.org/quarterly/830416donabedian.pdf

European Union. (2004). *Summary of EU Legislation Regarding the Development of High-quality, Accessible and Sustainable Health Care and Long-Term Care.*

> Social protection is a way of distributing, at the level of an entire society, costs which often exceed the means of an individual or his/her family, ensuring that even those on a low income have access to care. The social protection systems in the Member States have considerably reduced the risk of poverty and helped to improve the state of health of the people of Europe. They are therefore an important part of the European social model.

Link:http://europa.eu/legislation_summaries/employment_and_social_policy/social_protection/c10122_en.htm

Expert Advisory Panel to Review Publicly Funded Health Services. (2003). *The Burden of Proof: An Alberta Model for Assessing Publicly Funded Health Services.*

> This report outlines the Panel's recommendations for a new appraisal process for health technologies and services in Alberta. The proposed process is comprehensive and rigorous and would make Alberta a leader in appraisal of health services, treatments, and technologies in Canada. It would streamline and replace some of the ad hoc committees and decision-making processes currently in place. The process would be open and transparent to all parties, including the public, so people would know the outcomes of appraisals and the reasons why certain services or treatments are recommended or not recommended for public funding. Perhaps most important, it would assure Albertans that the best decisions are made and provide the best value from the basket of health services funded in the province.

Link: http://www.health.alberta.ca/documents/Assessing-Funding-Report-2003.pdf

Hussey, Peter, et all. (2010). *Feasibility and Design Options for a Potential Entity to Research the Comparative Effectiveness of Medical Treatments.*

> This report outlines several design options that Massachusetts could follow in establishing an interstate CEC. The choice of design option will be determined by the specific objectives of the legislature and by the legislature's prioritization of comparative effectiveness research over other options under consideration for improving quality and reducing spending growth in health care.

Link: http://www.rand.org/pubs/technical_reports/2010/RAND_TR803.pdf

Institute of Medicine of the National Academies. (2006). *Performance Measurement: Accelerating Improvement.*

> In 2001, the Institute of Medicine (IOM) released the report *Crossing the Quality Chasm: A New Health System for the 21st Century* (IOM, 2001). That report identified six aims for the health care system—health care should be safe, effective, patient-centered, timely, efficient, and equitable—and challenged the health care sector to achieve substantial improvements in each of these dimensions of quality over the coming decade. The report acknowledged that achieving significant improvement in quality across all six dimensions would necessitate behavioral and structural change at many levels, including patient–clinician relationships, small practice settings, health care organizations (e.g., hospitals and health plans), and the environment of care (e.g., regulatory processes and payment policies) (Berwick, 2002).

Link: http://www.nap.edu/openbook.php?record_id=11517&page=R1

Morone, James and Belkin, Gary (ed). (1994). *The Politics of Health Care Reform: Lessons from the Past, Prospects for the Future.*

This ambitious work helps explain why the American public should have expected the passage of health care reform legislation by the 103rd Congress and the Clinton administration. The book assesses health care politics in the United States, political institutions related to health care, the relation between business and health care, the relation between federal and state governments with respect to health care, and lessons from other countries that might apply to the United States.

Link:http://www.questia.com/read/11224287?title=The%20Politics%20of%20Health%20Care%20Reform%3a%20Lessons%20from%20the%20Past%2c%20Prospects%20for%20the%20Future

Ramsay, C. and Esmail, N. (2004). *The Alberta Health Care Advantage: An Accessible, High Quality, and Sustainable System.*

Already, by contracting out certain publicly insured procedures to private health facilities, Alberta is seen by many people as violating the national health act—even though it is not. But Alberta would be contravening the provisions against extra billing and user charges contained within the act if it did implement user fees, so the key word in Klein's quote, perhaps, is that the province will live up to the CHA's fundamental principles, but not necessarily the specific rules and regulations surrounding them. The impetus for such controversial action and the possible consequences of it are two key aspects of this study, which begins with a brief discussion of the basic economics of health care and the implications of the CHA for meaningful health care reform in Canada.

Link: http://www.fraserinstitute.org/commerce.web/product_files/AlbertaHealthCare.pdf

Skinner, Brett. (2009). *Canadian Health Policy Failures: What's Wrong? Who gets Hurt? Why Nothing Changes.*

Canadian health policy is increasingly failing patients and taxpayers. Canadians spend a lot on health care relative to comparable countries, yet our high relative level of spending does not buy Canadians as many health care resources as patients in other countries enjoy. Shortages of medical resources, as well as improper economic incentives within the Canadian health system, have resulted in growing waits for access to publicly funded, medically necessary goods and services. The available evidence indicates that wait times are longer in Canada than in almost all other comparable countries. Not only has our high level of spending not produced better access to health care, government health spending has also been growing at rates that are faster than our ability to pay for it through public means alone. This has resulted in health care consuming ever greater shares of the revenue available to governments, leaving proportionally less available for other public responsibilities and obligations.

Link:
http://www.fraserinstitute.org/commerce.web/product_files/CanadianHealthPolicyFailures.pdf

The Conference Board of Canada. (2004). *Challenging Health Care System Sustainability: Understanding Health System Performance of Leading Countries.*

The purpose of this report is to provide insights for key decision-makers on the performance, productivity and management practices of health care in other OECD countries. The focus is on Switzerland, Sweden, Spain, France, Australia and New Zealand.

Link: http://www.health.alberta.ca/documents/Sustainable-system-CBC-2004.pdf

Health Care Systems

Ahmed, A. and Fincham, J. (2010). *Physician Office vs. Retail Clinic: Patient Preferences in Care Seeking for Minor Illnesses.*

> Retail clinics are a relatively new phenomenon in the United States, offering cheaper and convenient alternatives to physician offices for minor illness and wellness care. The objective of this study was to investigate the effects of cost of care and appointment wait time on care-seeking decisions at retail clinics or physician offices.

Link:
http://www.annfammed.org/cgi/reprint/8/2/117?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=%22universal+design%22%3A&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT

Canadian Health Services Research Foundation. (2010). *Effective Governance for Quality and Patient Safety in Canadian health care Organizations.*

> The following report presents case studies for quality and patient safety in Canadian health care organizations.

Link: http://www.chsrf.ca/pdf/Case_Study_Annex_FINAL.pdf

Canadian Institute for Health Information. (2001). *Health Care in Canada.*

> As part of this commitment, CIHI has once again joined forces with Statistics Canada to report on the health of Canadians and on the health of our health care system. This report, *Health Care in Canada 2001*, focuses on the health care system. Its companion report, *How healthy are Canadians 2001?* focuses on the health status of Canadians and the factors affecting their health.

Link: http://secure.cihi.ca/cihiweb/products/Hlthrpt2001.pdf

Canadian Institute for Health Information. (2003). *The Changing Hospital.*

> Hundreds of "H" signs still line Canada's highways, but the hospitals they point travelers to are very different than they were a decade or even five years ago. For example, fewer patients are staying overnight, but day surgeries are on the rise. The number of hospital beds and the number of hospitals have also fallen. Between 1995.1996 and 1999.2000, 275 hospitals closed, merged, or changed to provide other types of care. Administration of hospitals has changed as well. In most parts of the country, health regions are now responsible for providing acute care services. They also manage long-term care, public and community health services, some mental health programs, and other types of care.

Link: http://secure.cihi.ca/cihiweb/products/hcic2003_Ch6_e.pdf

Canadian Institute for Health Information. (2007). *Canada's Health Care Providers, 2007.*

> In 2001, CIHI released *Canada's Health Care Providers*, which provided an overview of the health human resources (HHR) landscape in Canada at the time. The report described the health care workforce and highlighted trends based on available data. In 2005, CIHI provided an update entitled *Canada's Health Care Providers: 2005 Chartbook*. This third report in the series—*Canada's Health Care Providers, 2007*—builds on the work of the first two reports.

Link: http://secure.cihi.ca/cihiweb/products/HCProviders_07_EN_final.pdf

Canadian Institute for Health Information. (2008). *Health Care in Canada 2008.*

> *Health Care in Canada 2008* (HCIC 2008) is the ninth in a series of annual reports on the health care system and the health of Canadians. This year, HCIC 2008 provides a review of key analytic work undertaken at CIHI that highlights CIHI's health care research priorities (access, quality of care, costs, health human resources and population mental health). Also included in this report are key findings from seminal Canadian and international health care research as they relate to these health care priorities. HCIC 2008 is a reference tool to identify current priorities in health care for health researchers, persons involved in strategic decision-making in health care, the media and Canadians in general.

Link: http://secure.cihi.ca/cihiweb/products/HCIC_2008_e.pdf

Canadian Institute for Health Information. (2009). *Health Care in Canada 2009: A Decade in Review.*

> *Health Care in Canada 2009* (HCIC 2009) is the 10th anniversary edition in a series of annual reports on the health care system and the health of Canadians. As the 10th edition, HCIC 2009 offers a decade-long perspective on how the health care system has changed since the production of the very first in this series of reports. As with previous reports, this report draws on information and data held both within and external to CIHI. It provides a retrospective look at many health care priorities such as access, costs and quality of care, and the health care workforce and how these have changed since 1998–1999. Where possible, our retrospective look includes 10 years of data and trends. In some places, however, we have had to consider shorter trends due to data availability and comparability.

Link: http://secure.cihi.ca/cihiweb/products/HCIC_2009_Web_e.pdf

Cohen, Richard. (2007). *Accessible Health Care.*

> By stipulating that health care must be accessible, universal and publicly administered, the Canada Health Act de facto ensures that people with disabilities are not denied health care coverage or do not have their coverage loaded (i.e., higher premiums to reflect greater actuarial risk). Although health care funding in Canada is not calculated actuarially, its costs are shared by all Canadians through their taxes.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1764786/?tool=pubmed

Flood, Colleen. (2001). *Profiles of Six Health Care Systems: Canada, Australia, the Netherlands, New Zealand, the UK, and the USA.*

> Canada is not alone in struggling with the complexities of managing and ensuring the sustainability of an equitable health care system. In this paper we take a snapshot look at the health systems in six different countries. The goal is to identify the salient lessons for Canada in terms of its own health reform agenda and where further research and study would prove fruitful for Canadian policymakers.

Link: http://www.parl.gc.ca/37/1/parlbus/commbus/senate/com-e/soci-e/rep-e/volume3ver1-e.pdf

Harris, L. (ed). (1995). *Health and the New Media: Technologies Transforming Personal and Public Health.*

> As the nation has wrestled with new initiatives in health care and information infrastructure, we already see patterns of growth that form a useful basis for forecasting what an American health care system might look like by the year 2000. Yet the field remains a rich and uncharted frontier that beckons the scientist, the policy maker, and the entrepreneur to make critical contributions.
>
> This book is the best compendium of these first forces, which will help determine the scope and potential of the emerging interactive media as they are being applied to health concerns. The distinguished authors, all pioneers in their own fields, describe such things as member-centered managed care, demand management, telemedicine, provider teamwork, patient involvement in health care decision making, reinventing government, new media pedagogy, interactive health education in schools, simulation in health education, and the new dynamics of public-private sector responsibilities. For readers who are struggling to understand health from the perspective of the new media, or the new media from the perspective of health, this book will help them knit together the early vectors of managed care, a reinvented public health and health education, an empowered public, and the interactive media into a tapestry of their own making on which future contributions will be made.

Link:
http://www.questia.com/read/9597518?title=Health%20and%20the%20New%20Media%3a%20Technologies%20Transforming%20Personal%20and%20Public%20Health

Kluge, Eike-Henner. (2007). *Comparing health care Systems: Outcomes, Ethical Principles, and Social Values.*

> The question of how health care should be structured has been at the forefront of public debate for quite some time. In particular, debate has raged over the acceptability of socialized and rights-oriented approaches to health care as opposed to privatized and commodity-oriented approaches. The present discussion looks at the underlying logic of the debate and at the use of outcome measures as a primary determinant. It suggests that outcome measures are of limited use in deciding the issue because they ignore important variables and further suggests that outcome measures are inappropriate tools when comparing distinct health care systems because they ignore valuational components that are integral to deciding whether a health care system is consistent with a society's principles and values.

Link: http://www.medscape.com/viewarticle/564144

Kluge, Eike-Henner. (2007). *Resource Allocation in health care: Implications of Models of Medicine as a Profession.*

> For decades, the problem of how to allocate health care resources in a just and equitable fashion has been the subject of concerted discussion and analysis, yet the issue has stubbornly resisted resolution. This article suggests that a major reason for this is that the discussion has focused exclusively on the nature and status of the material resources, and that the nature and role of the medical profession have been entirely ignored. Because physicians are gatekeepers to health care resources, their role in allocation is central from a process perspective. This article identifies 3 distinct interpretations of the nature of medicine, shows how each mandates a different method of allocation, and argues that unless an appropriate model of medicine is developed that acknowledges the valid points contained in each of the 3 approaches, the allocation problem will remain unsolvable.

Link: http://www.medscape.com/viewarticle/551802

Health Care Expenditures

Canadian Institute for Health Information. (2009). *National Health Expenditure Trends, 1975 to 2009.*

> Both the public and private sectors finance Canada's health system. Public-sector funding includes payments by governments at the federal, provincial/territorial and municipal levels and by workers' compensation boards and other social security schemes. Private-sector funding consists primarily of health expenditures by households and private insurance firms.
>
> The Canadian Institute for Health Information (CIHI) tracks health care spending by each source of finance in the National Health Expenditure Database (NHEX). This database contains a historical series of macro-level health expenditure statistics by province and territory. CIHI assumed responsibility from Health Canada for the national health accounts, including NHEX, in 1995.

Link:
http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=download_form_e&cw_sku=NHEX2009EPDF&cw_ctt=1&cw_dform=N

Health Indicators

Canadian Institute for Health Information. (2004). *The Health Indicators Project: The Next 5 Years.*

> Interest in sound health information and health indicators, has never been higher. Health indicators can be used to inform health policy, manage the health care system, enhance our understanding of the broader determinants of health, as well as to identify gaps in the health status and outcomes for specific populations. While there are an infinite number of indicators that could be calculated, which ones are the most important to measure and track and what types of indicators best reflect the needs of those who use them? These and other questions were discussed at the 2004 Second Consensus Conference on Population Health Indicators. The results of this conference, and what has happened since then, are summarized in this report.

Link:
http://secure.cihi.ca/indicators/2005/en/downloads/March_2004_Conference_Report_e.pdf

Canadian Institute for Health Information. (2006). *Pan-Canadian Primary Health Care Indicator Project: Indicators.*

> The following list of pan-Canadian primary health care (PHC) indicators was developed for the National Evaluation Strategy through the PHC Indicator Development Project.

Link: http://secure.cihi.ca/cihiweb/en/downloads/Final_PHC_Indicator_List_-_Labels_-_Mar_29_2006_E.pdf

Canadian Institute for Health Information. (2006). *Pan-Canadian Primary Health Care Indicators: Report 1, Volume 2.*

Primary health care (PHC) has been called the foundation of Canada's health system and is the most common type of health care that Canadians experience.1 The Primary Health Care Transition Fund (PHCTF) was established in September 2000 as a shared commitment between federal and provincial/territorial governments to work together on improving PHC across the country, and to explore new ways of delivering PHC. Currently, we know little about how the structure of our PHC system is evolving or about the way services are delivered and the results of these services. Measuring PHC renewal in Canada requires harnessing and enhancing data sources at the local, regional, provincial/ territorial and pan-Canadian levels. PHC indicators and the data required to report these indicators can contribute to the measurement and management of PHC in Canada.

Link: http://secure.cihi.ca/cihiweb/products/PHC_Indicator_Report_1-Volume_2_Final_E.pdf

Canadian Institute for Health Information. (2009). *Health Indicators 2009.*

Since 1999, CIHI and Statistics Canada have collaborated on the Health Indicators project, developing and providing a broad range of indicators for health regions across the country. The first *Health Indicators* report was released in 2000, published along with *Health Care in Canada*. At that time, the report included 13 indicators, providing the first-ever comparative data on a range of health and health system measures for Canada's 63 largest health regions as well as the provinces and territories. The goal was to provide objective and up-to-date information to support evidence-based decision-making for regional, provincial and national stakeholders. The indicators were to help answer two questions: how healthy are Canadians, and how healthy is the Canadian health care system? This year, CIHI and Statistics Canada celebrate the 10th release of this report—*Health Indicators 2009*.

Link: http://secure.cihi.ca/cihiweb/products/Healthindicators2009_en.pdf

Health Policy Framework

Alberta Health and Wellness. (2006). *Getting on with Better Health Care: Health Policy Framework.*

Albertans place great value on their health system. They have told their government that they expect the health system to provide them with high quality care and to ensure that they have access to prompt and effective treatment. Albertans also want their health system to be sustainable and affordable. Albertans accept the Canada Health Act principles of comprehensiveness, universality, accessibility, portability and public administration; however, they view these principles as part of a larger framework of values and beliefs. The values of Albertans include: (1) patient-focused health care; (2) delivery of quality health services; (3) timely and fair access to services; (4) accountability for sound evidence-based investments, fiscal management and responsive service; and (5) increased choice and control over one's own health and wellness. The purpose of this Health Policy Framework is to provide health system leaders and governors with the needed support and guidance as they tackle some of the difficult challenges and search for ways to better organize, deliver and pay for health services. Innovative policy directions are needed to guide the evolution of the health system in ways that will put it on a more sustainable footing while responding to the values and expectations of Albertans. These ten policy directions are not stand-alone. They are all related and progress must be made on each one to achieve the intent of the policy framework.

Link: http://www.health.alberta.ca/documents/Better-Health-Care-2006.pdf

Alberta Health and Wellness. (2006). *Health Policy Framework.*

> The purpose of this Health Policy Framework is to provide health system leaders and governors with the needed support and guidance as they tackle some of the difficult challenges and search for Released in February 2006, Alberta's Health Policy Framework itemized ten new policy directions for sustainable, flexible and accessible health services for Albertans. The framework was created to guide government and health care partners in making positive, innovative changes to the public health care system that work for Albertans and Alberta's health care providers.

Link: http://www.health.alberta.ca/documents/Health-Policy-Framework-2006.pdf

Alberta Health and Wellness. (2006). *What We Heard from Albertans during March 2006.*

> The Alberta Government announced the *Getting on with Better Health Care* package in July, 2005. This package contained 13 actions to improve the health care system. These actions include the priorities areas of access, continuing care, wellness, mental health, primary health care, children's health, pharmaceuticals, electronic health records and rural health. One of the actions included developing a *Health Policy Framework* to set the overall direction this government will take to protect the public health system. The *Health Policy Framework* was released in February, 2006 with ten policy directions to improve the performance and sustainability of Alberta's health system. Many Albertans have taken the time to express their views and offer their ideas on the *Health Policy Framework*. This report describes the findings from the consultations.

Link: http://www.health.alberta.ca/documents/What-We-Heard-Report-2006.pdf

Stange, Kurt. (2010). *Power to Advocate for Health.*

> This is the seventh and final editorial in a series about integrative approaches to promoting health and personalized, high-value health and personalized, high-value health care. This editorial examines how we can develop the power to act on key values, knowledge, and principles to advance health for people, communities, and the population. This article asks the following questions:
> 1. What is moral authority and why is it important?
> 2. How can we understand the process for developing moral authority to advocate for health?
> 3. How might we act differently as individuals and as organizations if we developed this moral authority?
> The article concludes with a summary of the 7 pieces in this editorial series and an invitation to join the online discussion.

Link:
http://www.annfammed.org/cgi/reprint/8/2/100?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=%22universal+design%22%3A&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT

The Government of Alberta. (2006). *Health Policy Framework.*

> Albertans place great value on their health system. They have told their government that they expect the health system to provide them with high quality care and to ensure that they have access to prompt and effective treatment. Albertans also want their health system to be sustainable and affordable. Albertans accept the Canada Health Act principles of comprehensiveness, universality, accessibility, portability and public administration; however, they view these principles as part of a larger framework of

values and beliefs. The values of Albertans include: (1) patient-focused health care; (2) delivery of quality health services; (3) timely and fair access to services; (4) accountability for sound evidence-based investments, fiscal management and responsive service; and (5) increased choice and control over one's own health and wellness. The purpose of this Health Policy Framework is to provide health system leaders and governors with the needed support and guidance as they tackle some of the difficult challenges and search for ways to better organize, deliver and pay for health services.

Link: http://www.health.alberta.ca/documents/Health-Policy-Framework-2006.pdf

Health Workforce Planning

Alberta Health and Wellness. (2003). *Provincial Comprehensive Health Workforce Plan.*

The framework identifies some of the existing strategies for health workforce planning that are ongoing in Alberta. It is important to note existing strategies should have accountabilities, performance measures and targets built into them and should continue within the mandate set out for the strategy. The creation of accountabilities / performance measures / targets are the responsibility of organizations utilizing this framework. The comprehensive health workforce planning committee recognizes that this framework is only the base that organizations must consider when developing health workforce plans and that there may be additional building blocks that may be added in order to respond to particular system or organizational needs.

Link: http://www.health.alberta.ca/documents/Workforce-Plan-2003.pdf

Home Care

Canadian Institute for Health Information. (2004). *Development of National Indicators and Reports for Home Care: Final Project Report.*

This report is the final project report of Phase 2 of the *Development of National Indicators and Reports for Home Care Project* undertaken by the Canadian Institute for Health Information (CIHI). The aims of this phase were to further enhance of the indicators developed in Phase 1 and to conduct a National Pilot Test (NPT) of a minimum reporting data set to populate the indicators.

Link: http://secure.cihi.ca/cihiweb/products/HC_NPT2004_e.pdf

Impact of the Aging Population

Alberta Seniors and Community Supports. (1999). *Alberta Seniors and Community Supports.*

This report provides a summary of the written feedback received by the Steering Committee for the Government-Wide Study on the Impact of the Aging Population in the fall of 1999.

Link:http://www.seniors.alberta.ca/policy_planning/archives/aging_study/impact/survey&submissions.pdf

Christensen, K. et al. (2009). *Ageing Populations: The Challenges Ahead.*

> If the pace of increase in life expectancy in developed countries over the past two centuries continues through the 21st century, most babies born since 2000 in France, Germany, Italy, the UK, the USA, Canada, Japan, and other countries with long life expectancies will celebrate their 100th birthdays. Although trends differ between countries, populations of nearly all such countries are ageing as a result of low fertility, low immigration, and long lives. A key question is: are increases in life expectancy accompanied by a concurrent postponement of functional limitations and disability? The answer is still open, but research suggests that ageing processes are modifiable and that people are living longer without severe disability. This finding, together with technological and medical development and redistribution of work, will be important for our chances to meet the challenges of ageing populations.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2810516/pdf/nihms164804.pdf

Mort, M., et al. (ed) (2008). *Ageing, Technology and Home Care: New Actors, New Responsibilities.*

> The aim of the conference was to discuss actual practices that actors are developing and problems they are confronting, and to draw on exchanges for setting a research agenda on questions that need further consideration. The conference was conceived of as a participative event.

Link: http://catalog.ensmp.fr/Files/Homecare_1res.pdf

Walters, K et al. (2000). *Assessing Needs from Patient, Carer and Professional Perspective: the Camberwell Assessment of Need for Elderly People in Primary Care.*

> The article describes the Camberwell Assessment of Need for the Elderly, which is a new tool.

Link: http://ageing.oxfordjournals.org/cgi/reprint/29/6/505

Independent Living

Nason, Edward et al. (2008). *Supporting Independent Living for Disabled People: An Evaluation of the Foundations for Living Project.*

> Over the last 15 years, both the demand for and suitability of residential care facilities for disabled people has been decreasing steadily, as Government policy has undergone a gradual shift towards enabling disabled people to live independently in the community. Against this background, the Papworth Trust identified the need for innovative ways to provide services for disabled people wishing to lead independent lives. The Foundations for Living (FFL) initiative is the Trust's response to this need.

Link: http://www.rand.org/pubs/technical_reports/2009/RAND_TR616.pdf

Spinal Cord Injury Solutions Network. (2008). *A Scoping Review of Disability Policy in Canada: Effects on Community Integration for People with Spinal Cord Injuries.*

> The purpose of this research is to begin a comprehensive survey of disability policy in Canada (including provincial and federal jurisdictions) with the potential to effect community integration for people with spinal cord injuries.

Link:[*http://chspr.queensu.ca/downloads/Reports/Disability%20Policy%20in%20Canada-final%20report-May09.pdf*](http://chspr.queensu.ca/downloads/Reports/Disability%20Policy%20in%20Canada-final%20report-May09.pdf)

International Classification of Functioning, Disability and Health

Canadian Institute for Health Information. (2002). *ICF Model in the Context of the AT Field.*

The article describes the ICF model in the context of assistive technology.

Link: http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_6B_e.pdf

Canadian Institute for Health Information. (2009). *International Statistical Classification of Diseases and Related Health Problems: Volume One – Tabular List.*

A classification of diseases may be defined as a system of categories to which morbid entities are assigned according to established criteria. There are many possible axes of classification and the one selected will depend upon the use to be made of the statistics to be compiled. A statistical classification of diseases must encompass the entire range of morbid conditions within a manageable number of categories.

The Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) is the latest in a series that was formalized in 1893 as the Bertillon Classification or International List of Causes of Death. A complete review of the historical background to the classification is given in Volume 2 of ICD-10. While the title has been amended to make clearer the content and purpose, and to reflect the progressive extension of the scope of the classification beyond diseases and injuries, the familiar abbreviation "ICD" has been retained. In the updated classification, conditions have been grouped in a way that was felt to be most suitable for general epidemiological purposes and the evaluation of health care.

Link: http://www.cihi.ca/cihiweb/en/downloads/ICD-10-CA_Vol1_2009.pdf

Hahn, Harlan. (2002). *The ICF and the ICICDH: Privacy, Paradigms, and Definitions.*

During the past three decades, a host of dedicated volunteers have participated in a global project under the aegis of the World Health Organization (WHO) to develop a classification system for disabilities and chronic health conditions. The endeavor may have extensive implications for the development of law and public policy in many nations. In many respects, the task, which was apparently intended to supplement the famous *International Classification of Diseases* (ICD), appeared to reflect a growing belief that the principal medical challenges of the future will consist of disabilities and other enduring health problems. The work has produced several documents thus far including the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) in 19801 and the *International Classification of Functioning, Disability, and Health* (ICF) in 2001. Unlike the definition of acute illnesses, which was facilitated by widespread acceptance of the so-called “germ theory” of disease, the goal of formulating the ICIDH and the ICF required researchers to engage in the study of unfamiliar concepts that precipitated numerous controversies.

Link: http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_3A_e.pdf

Kostanjsek, Nenad. *International Classification of Functioning, Disability and Health.: Implementation and Research.*

This is a PowerPoint presentation about the ICF.

Link: http://secure.cihi.ca/cihiweb/en/downloads/Nenad_Kostanjsek_WHO_Report.pdf

Lollar, D. and Simeonsson, R. (2006). *Rights, Rehabilitation, and Disability: ICF.*

This is a PowerPoint presentation about ICF, rehabilitation and disability rights.

Link: http://secure.cihi.ca/cihiweb/en/downloads/Rune%20Simeonsson%20-%20Rights%20Rehab%20&%20Disability.pdf

Noonan, V. et al. (2009). *Comparing the content of participation instruments using the International Classification of Functioning, Disability and Health.*

The concept of participation is recognized as an important rehabilitation outcome and instruments have been developed to measure participation using the International Classification of Functioning, Disability and Health (ICF). To date, few studies have examined the content of these instruments to determine how participation has been operationalized. The purpose of this study was to compare the content of participation instruments using the ICF classification.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2785762/pdf/1477-7525-7-93.pdf

Stucki, G. et al. (2002*). Application of the International Classification of Functioning, Disability and Health (ICF) in Clinical Practice.*

Rehabilitation medicine is dedicated to optimizing patient functioning and health. Models of functioning and health are the basis for clinical practice, teaching and research. The ICF (International Classification of Functioning Disability and Health, formerly ICIDH-2 http://www3.who.int/icf/icftemplate.cfm) is designed to record and organize a wide range of information about health and health-related states. Since the ICF has been developed in a worldwide comprehensive consensus process over the last few years and has recently been endorsed by the World Health Assembly as a member of the WHO Family of International Classifications, it is likely to become the generally accepted framework to describe functioning in rehabilitation. The ICF is intended for use in multiple sectors that include, besides health, education, insurance, labour, health and disability policy, statistics, etc. In the clinical context, it is intended for use in needs assessment, matching interventions to specific health states, rehabilitation and outcome evaluation. However, the ICF will have to be tailored in order to suit these specific uses. The joint use of the ICF and the International Classification of Diseases ICD-10, needs to be addressed when applying the ICF to rehabilitation medicine.

Link: http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_papers_4_e.pdf

Medical Equipment

Canadian Institute for Health Information. (2006). *Medical Imaging Technologies in Canada, 2006—Supply, Utilization and Sources of Operating Funds.*

The appropriate numbers, types, institutional setting and funding of medical imaging equipment in Canada are hotly debated issues. This Analysis in Brief presents the latest data on the availability of medical imaging equipment, as well as its setting, utilization and

sources of operating funds, and focuses on the most recent data from the 2006 National Survey of Selected Medical Imaging Equipment rather than on trends. Analysis of trends will be included in a more extensive report planned for 2007.

Link: http://secure.cihi.ca/cihiweb/products/mit_analysis_in_brief_e.pdf

Canadian Institute for Health Information. (2007). *Medical Imaging Technologies in Canada, 2006 – Supply, Utilization and Sources of Operating Funds.*

In the past century, we have witnessed dramatic technological changes in the field of medicine. The same is true for medical imaging. For example, X-rays were just starting to be used for medical purposes in the late 1890s. Today, radiologists can read X-rays and other diagnostic images produced thousands of kilometres away in a matter of minutes. Surgical procedures that once required several days of hospitalization are now being performed on an outpatient basis. And more sophisticated forms of medical imaging, such as the ability to generate images of almost any structure within the body, are becoming essential to the provision of general and specialized medical care and treatment.

Nevertheless, little is known about the actual use of these technologies in Canada. This report aims to address this gap. It is meant to serve as a consolidated reference of what we know about medical imaging across Canada, helping to inform decisions as we move forward. We look in particular at the numbers of different kinds of machines in Canada and how they are used, as well as the skilled health professionals who operate the equipment and interpret results. In general, we tend to focus on a selection of more recent imaging technologies for which the information base is strongest. Many of the issues that we highlight, however, may apply across the spectrum of imaging technologies.

Link: http://secure.cihi.ca/cihiweb/products/MIT_2007_e.pdf

Issaacson Kailes, J. and Mac Donald, C. (2009). *Importance of Accessible Examination Tables, Chairs and Weight Scales.*

Health care providers should have accessible examination tables, chairs and weight scales. This report describes the various needs and barriers.

Link: http://www.cdihp.org/briefs/1%20%20Brief-Exam%20Tables%20and%20Scales-FINAL%20Edition%204_4%208%2009.pdf

Kailes, June (2007). *Just Hop Up, Look Here, Read This, Listen Up, Don't Breathe & Stay Still! Access to Medical Equipment – Where are We?*

This report describes the results from data from the National Consumer Needs Assessment Survey on medical equipment; strategies for getting accessible medical equipment into offices of health providers, existing resources for accessible equipment (exam tables, chairs, scales, mammography); using tools to communicate with providers about accessible equipment needs; and the Research Engineering and Rehabilitation Center's next steps - designing new equipment, effecting change within the medical equipment and health care industry and health care public policy.

Link: http://www.bcm.edu/ilru/html/training/webcasts/archive/2007/01-04-JK.html

Leibs, Andrew. (2009). *Accessible Medical Equipment: Study Shows Key Gap, Solution in Providing Health Care for Disabled.*

The article describes the various barriers that people with disabilities experience in doctor's offices. Stepping up onto or supporting oneself on an examination table is

difficult for many with mobility limitations. Most doctors' offices lack wheelchair scales and the personnel to lift patients onto and off equipment. Many obese patients and wheelchair users find exams so exhausting or demeaning they stop seeking care altogether. Inaccurate weight readings can mean medication errors and missed warning signs (and treatment options), for conditions ranging from depression to cancer.

Link: http://public-healthcare-issues.suite101.com/article.cfm/accessible_medical_equipment#ixzz0cW9HA84N

Lishan, X. et al. (2007). *A Review of health care Devices: Moving Design from Object to User.*

This paper examines the design evolution of a selection of health care devices and identifies some characterizations in their design which could not be isolated at each point. Beginning from a problem to solution (functional); to the need for safety and comfort with an ergonomic approach; to include technology that replaces many mechanically-operated functional aspects; enabling design to integrate new materials or forms to be aesthetically appealing, understandable and user-friendly; then trying to solve the 'failure' of design through universal design. Sensory and symbolic attributes which are successful in enhancing interaction, experience, and emotions can be understood as a decisive factor shaping the future of health care devices. It concludes with implications that encourage designers to broaden their perspectives towards health care.

Link:http://www.sd.polyu.edu.hk/iasdr/proceeding/papers/A%20Review%20of%20Healthcare%20Devices.pdf

Mack, Kelly. (2005). *Accessible Medical Exam Tables: Just Ask.*

This article discusses the need for medical examination tables that are accessible for people who use wheelchairs. Midmark Corporation is a market leader in accessible examination tables, as the company conducted background research and consulted with experts on the Americans with Disabilities Act before marketing a table. From their research the company was able to identify the ideal high and low table needs, as 37 inches should be the high point, and 17 to 19 inches should be the low point. Midmark's table also features a scissor-lift mechanism for switching between height options.

Link: http://www.equalizers.org/issues/New_Mobility_Dec05.pdf

Quan, Kathy. (2008) *New Devices Meet Health Care Needs: Consumer Technology Expands to the Health Care Arena.*

The article describes that during International CES, the consumer electronic trade show of the Consumer Electronic Association, more and more medical and health care related products are being showcased. The article describes the various devices that were showcased during the January, 2008 trade show.

Link:http://healthfieldmedicare.suite101.com/article.cfm/new_devices_meet_health_care_needs

Schwier, E. and Issaacson Kailes, J. (2006). *Getting the Right Gear: Taking Charge of Obtaining Durable Medical Equipment.*

The annual Hospital Quality in America Study was released and shows a wide gap in the quality of care between the top performing hospitals and all others. The study included evaluation of 18 procedures and conditions.

Link: http://www.cdihp.org/GettingDME.html

Wilcox, S. (2003). *Applying Universal Design to Medical Devices.*

> As the trend toward minimizing patient time in the hospital continues, one notable consequence has been the migration of medical devices from medical facilities to patients' homes. This phenomenon means that, increasingly, the patient, rather than the medical professional, is the device user. The effect of this change on the design of many medical products is substantial.

Link: http://www.dscience.com/articles/MDDIJanO3UnivDesign.pdf

Winters, J. (2007). *Medical Instrumentation: Accessibility and Usability Considerations.*

> Two of the most important yet often overlooked aspects of a medical device are its usability and accessibility. This is important not only for health care providers, but also for older patients and users with disabilities or activity limitations. Medical Instrumentation: Accessibility and Usability Considerations focuses on how lack of usability and accessibility pose problems for designers and users of medical devices, and how to overcome these limitations. Divided into five broad sections, the book first addresses the nature and extent of the problem by identifying access barriers, human factors, and policy issues focused on the existing infrastructure. The subsequent sections examine responses to the problem, beginning with tools for usability and accessibility analysis and principles of design for medical instrumentation. Building on this foundation, the third section focuses on recommendations for design guidelines while the fourth section explores emerging trends and future technologies for improving medical device usability. The final section outlines key challenges, knowledge gaps, and recommendations from accomplished experts in the field presented at the recent Workshop on Accessible Interfaces for Medical Instrumentation. Integrating expert perspectives from a wide array of disciplines, Medical Instrumentation traces a clear roadmap for improving accessibility and usability for a variety of stakeholders and provides the tools necessary to follow it.

Link:http://books.google.com/books?id=y_GtESjOI5IC&dq=Medical+Instrumentation+Accessibility+and+Usability+Considerations&printsec=frontcover&source=bn&hl=en&ei=nQ9OS8qOL4PoM_uFxesM&sa=X&oi=book_result&ct=result&resnum=4&ved=0CBoQ6AEwAw#v=onepage&q=&f=false

People with Disabilities and Access Barriers

Sanford, J. and Bruce, C. (2006). *The Physical Environment as an Independent Measure: A Framework for Understanding the Role of Environmental Attributes in Activity and Performance Outcomes.*

> This is a PowerPoint presentation that explains the role of environmental attributes in activity and performance outcomes.

Link: http://www.cihi.ca/cihiweb/en/downloads/Jon%20A.%20Sanford%20-%20Environmental%20Factors.pdf

Scheer, J et al. (2003). *Access Barriers for Persons with Disabilities: The Consumer's Perspective.*

> This article delineates the scope and the nature of specific barriers people with disabilities face in obtaining needed health-care services. Access is generally defined as the use of services relative to the actual need for care; lack of access occurs when there is

a need for services but those services are not utilized (Aday, 1975). Barriers to access are those factors that contribute to preventing a person from utilizing a service when needed. Although many of the health-care needs of individuals with disabilities are similar to those of people without disabilities, the presence of a disabling condition can place the individual at greater risk for secondary conditions, higher utilization of downstream services, increased need for durable medical equipment, functional decline, decreased independence, and psychological distress than is found in the general population (Sutton & DeJong, 1998).

Link:
http://www.questia.com/read/5001705978?title=Access%20Barriers%20for%20Persons%20with%20Disabilities%3a%20The%20Consumer%27s%20Perspective

Human Resources Development Canada. (2000). *In Unison: A Canadian Approach to Disability Issues.*

This report sets the stage for governments, persons with disabilities, disability advocates, communities, employers, labour and the non-profit sector to jointly focus on disability issues. It builds on the framework document entitled *In Unison: A Canadian Approach to Disability Issues*, which was released in 1998, by federal, provincial and territorial ministers responsible for social services.

Link: http://www.socialunion.gc.ca/In_Unison2000/iu00100e.html

People with Disabilities and Health Services

Alberta Health Services. (2008). *Persons with Disabilities: Health Services Literature Review and Community Consultations.*

The purpose of this literature review and community consultation was to identify barriers to health care experienced by persons with disabilities and ways in which the Calgary Health Region may become more competent in meeting the needs of persons with disabilities. The literature focused on articles published since 2001 and the community consultation involved four focus groups with a total of 34 participants, including persons with disabilities (including communication, developmental, intellectual, physical and psychiatric disability), support workers, family members and representatives of organizations who work with persons with disabilities.

The research found that persons with disabilities, as a group, are more likely than able-bodied counterparts to have multiple and complex health care needs, in some cases leading to proper care not being provided; perceive their health status as poor; report having unmet health care needs (including reduced rates of preventive health care services); and have lower levels of satisfaction with health care. Focus groups, however, also revealed that many persons with disabilities have had exceptionally positive experiences with individual practitioners/providers.

This suggests that actions already being taken are helping to reduce barriers. Barriers to health care experienced by persons with disabilities were identified and organized into three types: environmental, process, and individual barriers. Each type of barrier was explored in depth and recommendations are made for enhancing the disability competency of health care systems.

Link:http://www.calgaryhealthregion.ca/programs/diversity/diversity_resources/research_publications/disabilities_report.pdf

Alston, R. et al. (2004). *Reform Laws and Health Care Coverage: Combating Exclusion of Persons with Disabilities.*

> The quest for accountability and efficiency of health care in the United States has been a priority for almost twenty-five years. With the passage of the Health Maintenance Organization Act in 1973 and the subsequent acceptance of the concept of diagnostic related groups, the federal government attempted to better regulate health care delivery (Schriner & Batavia, 1995). However, not until the last few years has national health care reform become the focus of intense analysis, discussion, and debate. For the public at large, and for persons with disabilities in particular, it was the Clinton administration's push for reform of health care that moved the issue to a new level of national awareness. Though the Clinton administration's attempt at national health care reform did not succeed, there have been changes in health care service delivery. For example, there is a continuing shift from the more traditional fee-for-service approach of health care to what has become known as the managed care approach.

Link:
http://www.questia.com/read/5002243819?title=Reform%20Laws%20and%20Health%20Care%20Coverage%3a%20Combating%20Exclusion%20of%20Persons%20with%20Disabilities

Bachman, S. et al. (2006). *Provider Perceptions of Their Capacity to Offer Accessible Health Care for People with Disabilities.*

> The purpose of this article is to provide preliminary data about the results of a comprehensive survey of providers regarding their perceptions of access to health care for people with a broad range of disabilities. We conducted a mail and telephone follow-up survey of providers that contract with two managed care organizations, the Massachusetts Division of Medical Assistance, and the Assisted Living Association (36% response rate). Data were analyzed using standard methods. Results suggest that providers are more likely to provide services to patients with chronic illness, mobility, cognitive, or psychiatric impairments than they are to serve individuals with communication limitations or visual impairments. Providers also reported that people with communication impairments are the most difficult to serve. However, respondent perceptions also suggest that individuals with disabilities do not have easy access to health-care providers, despite changes brought on by the Americans with Disabilities Act.

Link:
http://www.questia.com/read/5018547466?title=Provider%20Perceptions%20of%20Their%20Capacity%20to%20Offer%20Accessible%20Health%20Care%20for%20People%20with%20Disabilities

Batavia, Andrew. (1993). *Health Care Reform and People with Disabilities.*

> As a group, people with disabilities or chronic conditions experience higher-than-average health care costs and have difficulty gaining access to affordable private health insurance coverage. While the Americans with Disabilities Act will enhance access by prohibiting differential treatment without sound actuarial justification, it will not guarantee equal access for people in impairment groups with high utilization rates. Health care reform is needed to subsidize the coverage of such individuals. Such subsidization can he achieved under either a casualty insurance model, in which premiums based on expected costs are subsidized directly, or a social insurance model, in which low-cost enrollees cross-subsidize high-cost enrollees. Cost containment provisions that focus on the provider, such as global budgeting and managed competition, will adversely affect disabled people if providers do not have adequate incentives to meet these people's needs. Provisions

focusing on the consumer, such as cost sharing, case management, and benefit reductions, will adversely affect disabled people if they unduly limit needed services or impose a disproportionate financial burden on disabled people.

Link: http://content.healthaffairs.org/cgi/reprint/12/1/40.pdf

Branigan, M. et al. (2001). *Perceptions of Primary health care Services among Persons with Physical Disabilities. Part 2: Quality Issues.*

The ability of persons with disabilities to access quality primary care in Canada is not well documented. This article reports on the perceived quality of primary care received by persons with disabilities by looking at utilization of elements of the health maintenance examination, referrals, health promotion, health care provider role clarification, and satisfaction.

Link: http://www.medscape.com/viewarticle/408123

Canadian Institute for Health Information. (2007). *Health Status and Health Care in the Disability Community in Canada: Summary of Results.*

Recent international studies have shown that Canadians with disabilities are less healthy than their American and British counterparts. People with disabilities experience shorter life expectancy, take more disability days and tend to use more health services than their counterparts without disabilities. The research also shows that disabled people are often disadvantaged in terms of income, labour force participation, education and social opportunities. Given the relationship between socio-economic factors and health, it is important to understand how social, economic and health care system factors affect the health of people with disabilities. The purpose of this study was to provide population based information on the health of people with disabilities living in Canada.

Link: http://secure.cihi.ca/cihiweb/en/downloads/summary_mccoll_m_2007_e.pdf

Canadian Institute for Health Information. (2007). *The Burden of Neurological Diseases, Disorders and Injuries in Canada.*

Neurological diseases, disorders and injuries represent one of the leading causes of disability in the Canadian population. Very few neurological conditions are curable, and many worsen over time. They produce a range of symptoms and functional limitations that pose daily challenges to individuals and their families. In addition, neurological conditions pose an economic burden to society. Because the incidence of neurological conditions increases with age, this burden may magnify as Canada's population ages. To date, there has been little focus on the burden of neurological diseases, disorders and injuries in Canada. Recognizing this, the Canadian Brain and Nerve Health Coalition partnered with the Canadian Institute for Health Information and the Public Health Agency of Canada to create this report.

Link: http://secure.cihi.ca/cihiweb/products/BND_e.pdf

Center for Health Care Strategies, Inc. (2005). *A Training Program for Medical Professionals about Improving the Quality of Care for People with Disability.*

Medical professionals are increasingly required to have a broader view of the social, emotional, and political context of disability. They need to see disability as more than physical, cognitive, or emotional dysfunction. New models of the disability experience assert that a range of factors including environmental, architectural, logistical, societal, and cultural influences define and impact the health and wellness of disabled individuals,

at least as much as their biologic impairments. This training program is geared for managed care professionals. It offers practitioners, including physicians and nurses, as well as ancillary, social service and support staff, an introduction to crucial issues that affect the quality of care for patients with physical, sensory and communication disabilities. This program does not address the unique needs of people with cognitive disabilities, such as mental retardation or traumatic brain injury or psychiatric disability, nor does it address care of children with disabilities.

Link: http://www.chcs.org/usr_doc/99911Final4-05.pdf

Chesson, R. and Sutherland, A. (1992). *General Practice and the Provisions and Services for Physically Disabled People Aged 16 to 65 Years.*

The study reported here was part of a larger survey investigating the nature and extent of disability in the Grampian region. Interviews with 212 people aged between 16 and 65 years who had a wide range of physical disabilities elicited perceptions of current and past service provision. Respondents expressed a strong need for information on disability services and reported difficulty in knowing whom to approach for this. General practitioners were the most commonly reported source of such information and low usage of the Department of Social Security, social work departments and voluntary organizations was identified. The need to reevaluate the role of the general practitioner in the provision of information and services is discussed.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1372271/pdf/brjgenprac00050-0027.pdf

Edwards, L., Krassioukov, A. and Fehlings, MG. (2002). *Importance of Access to Research Information among Individuals with Spinal Cord Injury: Results of an Evidenced-Based Questionnaire.*

The majority of SCI patients have a high interest in accessing SCI research information. The Internet is favourable, comfortable and accessible tool for providing this information and will benefit all SCI patients. These results suggest that a significant number of patients with SCI would benefit from an accessible Internet-based information database that is relevant to the SCI patients population.

Link: http://www.nature.com/sc/journal/v40/n10/pdf/3101364a.pdf

Francis, L. and Silvers, A. (2008). *Debilitating Alexander V. Choate: "Meaningful Access" to Health Care for People with Disabilities.*

Since 1985, Alexander v. Choate (1) has stood for the proposition that financially-motivated limitations and cutbacks in state-provided health care services imposing significant negative impacts on people with disabilities are very difficult to challenge successfully under the Rehabilitation Act of 1973 ("Rehabilitation Act") (2) and, for similar reasons, under the Americans with Disabilities Act of 1990 ("ADA"). (3) During the twenty years following the Choate decision, acquiescence in this proposition has largely prevailed. (4) This discouraging picture, however, reads Choate far too expansively. In this Article, we develop a strategy for addressing and, we hope ultimately, circumscribing Choate's influence and debilitating its effects.

Part I of this Article analyzes in detail the Court's decision in Choate. Part II then establishes how a wide array of cases, both in and out of the health care area, have explained the meaningful access requirement under the ADA, which the Choate Court analyzed in terms of the equal opportunity to make use of or enjoy a benefit or service. Part III suggests, in light of several examples, that understanding meaningful access in

terms of equality of opportunity may provide a blueprint for success despite Choate. Finally, this Article concludes that the meaningful access standard should be understood in terms of fair equality of opportunity. This reading brings Choate in line with Congress's goal in passing the ADA to provide equal opportunity for people with disabilities.

Link: http://www.questia.com/read/5027722057?title=Debilitating%20Alexander%20V.%20Choate%3a%20%22Meaningful%20Access%22%20to%20Health%20Care%20for%20People%20with%20Disabilities

Government of Canada. (2003). *Defining Disability: A Complex Issue.*

This document provides a review of, and framework for understanding, disability definitions in key Government of Canada initiatives.

Link: http://dsp-psd.communication.gc.ca/Collection/RH37-4-3-2003E.pdf

Great Lakes ADA Center. (2007). *Medical Examinations and Inquiries under the Americans with Disabilities Act.*

While the ADA's provisions covering disability-related inquiries and medical examinations have not resulted in as much litigation as other provisions of the ADA, such as the definition of disability, several interesting issues have been examined by the courts. This Legal Brief will review the legal issues related to disability-related inquiries and medical examinations that have been the subject of litigation, and the court decisions interpreting those issues.

Link: http://www.ada-il.org/resources/Great%20Lakes%20Subcontract%20Brief%20-%20Disability%20Inquiries%20and%20Medical%20Exams%20Legal%20Brief%204-30-07.doc

Hanson, K et al. (2003). *Understanding the Health-Care Needs and Experiences of People with Disabilities: Findings from a 2003 Survey.*

The data presented in this report are based on a national, telephone survey of 1,505 non-elderly adults ages 18-64 with permanent physical and/or mental disabilities. The sample was drawn from a nationally representative survey of households to identify individuals with disabilities. Households were contacted through random-digit dialing and screened between June 19, 2002, and January 28, 2003, and the survey interviews were conducted between January 9 and February 11, 2003. International Communications Research, Inc. (ICR), conducted the fieldwork and the survey instrument was developed by a team of researchers at ICR and The Henry J. Kaiser Family Foundation.

Link: http://www.kff.org/medicare/upload/Understanding-the-Health-Care-Needs-and-Experiences-of-People-with-Disabilities-Findings-from-a-2003-Survey.pdf

Howe, T. and Worrall, Linda. (2006). *Environmental Factors and People with the Language Disorder of Aphasia.*

This is a PowerPoint presentation that explains the issues and barriers that people with aphasia face.

Link: http://secure.cihi.ca/cihiweb/en/downloads/Tami%20Howe%20-%20Oral%20Health%20&%20the%20Environment.pdf

Kinnee, S. et al. (2004). *Prevalence of Secondary Conditions Among People With Disabilities.*

> One in 5 Americans reports disability or limitation in major life activities because of physical, mental, or emotional conditions lasting 6 or more months. Disability is increasing as the population ages with chronic conditions and more young people survive birth- and injury- related limitations. People with disabilities are at risk for "secondary conditions," preventable physical, mental, and social disorders resulting directly or indirectly from an initial disabling condition. There is agreement that prevention of secondary conditions should be a major component of health promotion for people with disabilities. What is known about the prevalence of these conditions comes from clinical studies of patients and convenience samples. This article reports the first effort to collect data on population prevalence and impact of common secondary conditions.

Link: http://www.medscape.com/viewarticle/470375

Lindsey, Mary. (2002). *Comprehensive Health Services for People with Learning Disabilities.*

> Comprehensive health care services respond effectively to the needs of their patients not just in terms of treatment of health problems but also by addressing overall well-being by understanding, informing, involving, counselling and respecting the individual. By contrast, the history of health care for people with learning disabilities has been characterised by a lack of communication and poor understanding of their ordinary and special needs. There have been many barriers to access to health services that most members of the population take for granted. In addition, people with learning disabilities have many special health care needs that also have to be addressed. Therefore, person-centred services must be aware of the wide range of needs to which they must be able to respond while treating each person as an individual.

Link: http://apt.rcpsych.org/cgi/reprint/8/2/138

Marks, M. and Teasell, R. (2006). *More than Ramps: Accessible Health Care for People with Disabilities.*

> Recent discussions on health care in Canada have focused on 2 principal areas: the use of private services and the potential emergence of a 2-tier health system, and wait times for services. However, to consider the accessibility of health care for people with disabilities is to see that Canada already has a 2-tier health system. As important as timely access to care may be, of prime concern to this patient population is their access to medically necessary care. In spite of their potential complexity, many of the basic health care needs of people with disabilities are the same as those of the general population. Yet people with disabilities do not receive the same level of primary and preventive care as others do. Routine interventions such as a Pap smear or prostate exam are not consistently provided to them. Even more disturbing, people with disabilities are 4 times as likely as able-bodied people to report an inability to obtain required medical care when it is needed.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1534102/?tool=pubmed

Morrison, E. et al. (2008). *Primary Care for Adults With Physical Disabilities: Perceptions From Consumer and Provider Focus Groups.*

Family physicians lack data on how best to address the needs of adults with physical disabilities. We undertook this study to understand how consumers, educators, and other professionals perceive primary care for people with disabilities.

Link: http://www.stfm.org/fmhub/fm2008/October/Elizabeth645.pdf

National Council on Disability. (2009). *The Current State of Health Care for People with Disabilities.*

Primary barriers to health and health care for the general population are becoming well documented, and heightened national awareness of these obstacles has spurred numerous proposals for health care reform. Among the groups that face such barriers are Americans with disabilities. Even as information remains limited, recent studies indicate that people with disabilities experience both health disparities and specific problems in gaining access to appropriate health care, including health promotion and disease prevention programs and services. They also frequently lack either health insurance or coverage for necessary services such as specialty care, long-term care, prescription medications, durable medical equipment, and assistive technologies.

Although attempts have been made to address some of these barriers, significant problems remain. For example, Federal health care funding agencies such as the Centers for Medicare & Medicaid Services (CMS) do not conduct oversight of Americans with Disabilities Act (ADA) architectural and programmatic accessibility compliance by states, health plans, and medical providers or assess health providers' disability cultural competence. Few health care training programs address disability issues in their curriculums, and most federally funded health disparities research does not recognize and include people with disabilities as a disparity population. These and related challenges will affect the quality of life, productivity, and well-being of greater numbers of Americans as the population ages and the number of people with disabilities increases. Given these changes, it is especially important to understand the complex and interrelated factors that contribute to health and health care inequities for people with disabilities, and to identify practical solutions. NCD undertook "The Current State of Health Care for People with Disabilities" study to focus the nation's attention on these concerns and provide information and recommendations that will help guide the development of long-term solutions for Congress, the Administration, and other stakeholders, including health care organizations, insurers, health care providers, the health and disability research community, and people with disabilities. This chapter sets the stage for the report by introducing key problems and barriers to health and health care, and summarizing health trends for the nation's 54.4 million people with disabilities. It also sets forth the project's research questions and presents a brief overview of the research methodology NCD used to collect and evaluate information. The chapter provides a short discussion of the differences among disability, impairment, and health condition, and why these distinctions are important, especially for health and health care policy and research. The chapter concludes with a short road map, or overview, of the report.

Link:
http://www.ncd.gov/newsroom/publications/2009/HealthCare/HealthCare.html#Need%20for%20the%20Study

North Carolina Office on Disability and Health. *Partners in health care.*

Individuals with disabilities face the same health problems as all people but have the added responsibility of dealing with accessibility and health concerns related to their disability. From parking to being able to get onto an exam table, people with disabilities are faced with many obstacles at medical facilities. Consequently, those with disabilities are less likely to seek out and receive preventive health services as well as information

about their sexuality, pregnancy, parenting or aging. As a health care provider, you can make a real difference in promoting the health of a population that has been traditionally underserved. These steps will help you create more accessible environments and services and to engage people with disabilities as partners in care.

Link: http://www.fpg.unc.edu/~ncodh/pdfs/partners.pdf

Ouellette-Kuntz, Helene. (2006). *Commentary: Comprehensive Health Assessments for Adults with Intellectual Disabilities.*

While regular general health screening has been an expectation of preventative services, it is recognized that, to ensure efficient use of limited resources, protocols should be adapted to reflect the particular risk of individual patients or patient groups. In a Commentary in the Canadian Medical Association Journal titled 'Preventive care: so many recommendations, so little time', Nicholas Pimlott stresses the importance of basing priorities and practice on evidence of effectiveness. Furthermore, means of implementing recommendations for preventative services must consider the most appropriate roles for patients, caregivers, allied health professionals and primary care physicians. The authors of the guidelines concerning 'Preventive Services in Adults' stipulate that 'one-on-one interviews by clinicians are the least efficient way to obtain and update [needed] information'.

Comprehensive health assessments are no longer accepted at face value. One must consider both the evidence for inclusion of specific assessments for a given individual patient, and the evidence indicating how the assessment should be conducted.

Link: http://ije.oxfordjournals.org/cgi/reprint/36/1/147

Patrick, D et al. (1982). *Disablement and Care: A Comparison of Patient Views and general Practitioner Knowledge.*

A questionnaire was used to assess general practitioners' knowledge of handicaps and service use among disabled patients in a group practice. The disabled patients were identified by a postal screening questionnaire. Sixty eight were subsequently interviewed to assess the severity of restrictions on their activities and to collect information about informal support and use of community or hospital services. The areas of life in which the disabled were most affected by their medical conditions were sleep and rest, household management emotion and mood. Relatives assisted the disabled considerably with all daily activities but more help was requested. Most disabled patients had consulted their general practitioner or attended casualty and out patient clinics, but only a minority had used other community services. Prescription of drugs was considered the most important service the doctor provided. A second questionnaire, which the general practitioners completed with the help of their records, revealed that they knew of only 50 per cent of the difficulties with daily living reported by the disabled and even less of the aids, appliances and services used. A better awareness of these facilities among general practitioners might lead to a more effective distribution of resources among their patients.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1972508/pdf/jroyalcgprac00091-0047.pdf

Queensland Government. (2005). *A Way with Words: Guidelines for the Portrayal of People with Disability.*

The purpose of this booklet is to promote inclusiveness and the fair and accurate portrayal of people with a disability. It is intended as an aid for professional communicators, such as journalists, writers, producers and broadcasters, and provides

suggestions for appropriate language, interviewing techniques and media coverage involving people with a disability.

Link: http://www.disability.qld.gov.au/community/communication/way-words/documents/way_with_words.pdf

Rimmer, James. (1999). *Health Promotion for People with Disabilities: The Emerging Paradigm Shift from Disability Prevention to Prevention of Secondary Conditions.*

The premise of this article is that, until recently, health promotion for people with disabilities has been a neglected area of interest on the part of the general health community. Today, researchers, funding agencies, and health care providers and consumers are leading an effort to establish higher-quality health care for the millions of Americans with disabilities. The aims of a health promotion program for people with disabilities are to reduce secondary conditions (eg, obesity, hypertension, pressure sores), to maintain functional independence, to provide an opportunity for leisure and enjoyment, and to enhance the overall quality of life by reducing environmental barriers to good health. A greater emphasis must be placed on community-based health promotion initiatives for people with disabilities in order to achieve these objectives. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions.

Link: http://ptjournal.apta.org/cgi/reprint/79/5/495

Rubin, L. et al. (2007). *Delivery of Health Care for People with "Dual Diagnosis": From the Person to the Policy.*

This paper will examine the complexity and challenges in providing effective delivery of physical and mental health care to people with developmental disabilities. We will highlight a model of service delivery that focuses on "behavioral" crisis intervention and prevention which leads to a comprehensive set of interdisciplinary services and supports as well as a network of community linkages that facilitate the delivery of services. Suggestions will be offered for improving the systems of health care that will address the multiple levels of service delivery and ultimately improve the health care for people with intellectual and developmental disabilities more effectively and more efficiently and reduce the health disparities in our society.

Link:
http://www.questia.com/read/5028577132?title=Delivery%20of%20Health%20Care%20for%20People%20with%20%22Dual%20Diagnosis%22%3a%20From%20the%20Person%20to%20the%20Policy

Schickedanz, A. et al. (2009*). A Clinical Framework for Improving the Advance Care Planning Process: Start with Patients' Self-Identified Barriers.*

To explore barriers to multiple advance care planning (ACP) steps and identify common barrier themes that impede older adults from engaging in the process as a whole.

Link: http://www.medscape.com/viewarticle/586744

Trillium Health Centre. (2004). *Creating a Barrier-Free World: Annual Accessibility Plan 2004-2005.*

> Trillium Health Centre (Trillium) has been committed to the ongoing process of improving access to all of its facilities, programs, policies and services. Trillium welcomes the formal opportunity to create an Accessibility Committee and invite the participation of persons with disabilities in the development and review of its annual accessibility plans. We will conduct an ongoing review of both physical and attitudinal barriers to remove and prevent such barriers in our two hospital sites.

Link: http://www.trilliumhealthcentre.org/about/AccessibilityPlan2004_05_v2.pdf

The U.S. Equal Employment Opportunity Commission. (2008). *EEOC Enforcement Guidance on Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act.*

> This enforcement guidance explains when it is permissible for employers to make disability-related inquiries or require medical examinations of employees.

Link: http://www.eeoc.gov/policy/docs/guidance-inquiries.html

U.S. Department of Health and Human Services. (1998). *Meeting the Challenge of Serving People with Disabilities: A Resource Guide for Assessing the Performance of Managed Care Organizations.*

> Comprehensive systems for measuring the performance of health care systems in caring for persons with disabilities do not yet exist. At the same time, thousands of individual quality measures exist but it is often difficult to discern which will be most reliable and relevant to measure MCO performance in caring for people with disabilities. In these circumstances, it is easy to respond either by (1) doing little or nothing to measure MCO performance or (2) mounting costly efforts to measure hundreds of highly specific aspects of quality that may fail to provide a coherent picture of performance. This Resource Guide is designed to help those who want to begin to work toward a comprehensive system, today, by using measures available right now that have a clear relationship to domains of performance important to the care of persons with disabilities.

Link: http://aspe.hhs.gov/daltcp/reports/resource.pdf

Veltman, Albina et al. (2001). *Perceptions of Primary health care Services among People with Physical Disabilities. Part 1: Access Issues.*

> Access to primary health care among people with physical disabilities has been a neglected research area in Canada. The authors sought to examine the extent of access to and satisfaction with primary health care services for people with physical disabilities living in Canada's largest metropolitan area -- the Toronto region.

Link: http://www.medscape.com/viewarticle/408122

Woodcock, K. and Pole, Jason. (2007). *Health profile of deaf Canadians: Analysis of the Canada Community Health Survey.*

> To profile the health of deaf and hard-of-hearing Canadians in relation to the population as a whole.

Link: http://www.cfp.ca/cgi/reprint/53/12/2140

World Health Organization. (2009). *Access to Health Care Difficult for People with Disabilities.*

> People with disabilities make up more than 10% of the world's population. Too often though, they are unable to access health care services. This is not about just the physical access to buildings, but also access to services, information, care and support.

Link:http://www.who.int/mediacentre/multimedia/podcasts/2009/disability_access_20090220/en/index.html

Policy Research

Canadian Institute for Health Information. (2002). *Tools for Knowledge Exchange: Scanning Best Practices in Policy Research.*

> This working paper from the Canadian Population Health Initiative (CPHI) provides a snapshot of how a number of Canadian organizations that produce or are receptors of policy research describe their view of *best practices* in helping to ensure policy research uptake. Organizations considered leaders in health and social policy in Canada participated in a survey commissioned by CPHI in 2001.

Link: http://secure.cihi.ca/cihiweb/en/downloads/cphi_policy_practices_e.pdf

Primary Health Care

Alberta Health and Wellness. (2004). *Primary Health Care Discussion.*

> Primary health care is a concept that has captured the interest and attention of policy makers, providers and communities around the world over the past twenty years since it was defined and endorsed by the World Health Organization. Recent efforts to reform the health system across Canada have resulted in a renewed focus on primary health care. While specific definitions of primary health care vary in the current literature, they have in common, key concepts, elements and terminology. One common element is that primary health care involves the first contact an individual has with the health system. Primary health care, while recognizing the importance and need for intervention and care components of health, is also consistent with a stronger emphasis on determinants of health and population health strategies, disease and injury prevention, health promotion, and the active involvement of communities and individuals, in partnership with providers, regarding decisions that affect their health.

Link: http://www.health.alberta.ca/documents/Primary-Health-Care-discuss.pdf

Haggerty, J. et al. (2008). *Practice Features Associated with Patient-Reported Accessibility, Continuity, and Coordination of Primary Health Care.*

> In 2002, Family Medicine Groups (FMGs) were proposed as a new organizational model to enhance integration between private practices and community health centers. The FMG is a volunteer administrative arrangement for existing practices or networks of 8 to 10 physicians who are accredited by the regional health authority to provide a basket of planned services, have extended service hours (including evenings, Saturdays, and Sundays), and have formal agreements with other establishments to offer the full range of services to a population of registered patients. In turn, the FMG receives 1 or more nurses paid from the budget of the local community health center. These organizational features

are similar to those of primary health care models that are being introduced throughout Canada in an effort to strengthen primary health care.

Link: http://www.annfammed.org/cgi/reprint/6/2/116

Proposed Act

Bruno, R. (2009). *Act for Physical Access to Care.*

In this article, Dr. Bruno argues for the need to make *Physical Access to Health Care Act* the law.

Link: http://www.unitedspinal.org/publications/action/2009/05/15/act-for-physical-access-to-care/

California Citizens for Health Freedom. (2001). *Call for the Access to Medical Treatment Act (AMTA).*

The Access to Medical Treatment Act (AMTA) would allow an individual to be treated by any health care practitioner who is legally authorized to provide health services in the state in which the services are provided, with any method of medical treatment the individual desires, so long as the treatment causes no harm more serious than reactions experienced with routinely used medical treatments for the same medical conditions; and the patient is fully informed about the treatment and its possible side effects.

Link: http://www.citizenshealth.org/amta.htm

The Government of United States of America. (2005). *Access to Medical Treatment Act.*

The purpose of the Act was "to permit an individual to be treated by a health care practitioner with any method of medical treatment such individual requests, and for other purposes."

Link: http://www.govtrack.us/congress/billtext.xpd?bill=h109-2792

Rural Health Care Services

Lishner, D. et al. (1996). *Access to Primary Health Care among Persons with Disabilities in Rural Areas: A Summary of the Literature.*

Despite the prevalence of disabilities among persons living in rural areas, scarce data exist on their health care needs. While rural residents generally experience barriers to access to primary health care, these problems are further exacerbated for people with disabilities. This article summarizes findings from the published literature one access to primary health care among people with disabilities living in rural locations. A comprehensive computerized literature search turned up 86 articles meeting the study criteria, focused on the following rural populations affected by disabilities: children and adolescents, working-age adults, the elderly, the mentally ill, and people with AIDS. For each of these populations, substantial problems in accessing appropriate health care have been documented. The literature consistently emphasizes the failure of local health care systems in nonmetropolitan areas to adequately address the complex medical and related needs of individuals with disabilities. In the absence of specialized expertise, facilities, and primary care providers trained specifically to care for disabled persons, local programs rely heavily on the use of indigenous paraprofessionals and alternative models of care.

Further research is needed to identify and test the efficacy of innovative service delivery strategies to improve health care access for this population.

Link: http://www.amsa.org/programs/barriers/access.pdf

Jennissen, T. (1992). *Health Issues in Rural Canada.*

This paper examines two important issues. The first is the availability of and access to good quality health care in rural areas, paying particular attention to needs of women, children, youth, disabled persons, immigrants and elderly people. The second is the health problems unique to certain groups in specified rural areas: farmers on the prairies, Indians and Metis on reserves, and fishermen in single-industry towns in the Maritimes.

Link: http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/bp325-e.htm

New South Wales Government. *Rural Spinal Cord Injury Service.*

The goal is to ensure more equitable delivery of specialist spinal services in rural NSW, in partnership with local agencies and service providers.

Link: http://www.health.nsw.gov.au/gmct/spinal/rscis_background.asp

Surveys

Fougeyrollas, P. et al. (2006). *Subjective Measurement of Participation and Environmental Barriers and Facilitators in Population Surveys: Use of Standardized Tools with a Sub-Sample of the Quebec Activity Limitations Survey.*

Partial results of a research on Personal and Environmental factors associated to poverty progression of people with disabilities in Quebec.

Link: http://secure.cihi.ca/cihiweb/en/downloads/Patrick%20Fougeyrollas%20-%20ICF%20in%20Surveys.pdf

Universal Design

Berube, B. (1981). *Barrier-Free Design – Making the Environment Accessible to the Disabled.*

Designing barrier free environments for people with disabilities.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1705088/pdf/canmedaj01473-0070.pdf

Joines, S. (2009). *Enhancing Quality of Life through Universal Design.*

By focusing on challenges in the residence, this article will inform readers how rewriting problems and supporting solutions guided by the principles of universal design will enable individuals to complete more tasks. Although the individual's capabilities do not change as a result of the design, his/her abilities do.

Link: http://iospress.metapress.com/content/5g112p283123h141/fulltext.html

Steinfeld, E. and Danford, S. (2006). *Universal Design and the ICF.*

> How can you recognize a universal design? It is not simply a matter of providing an accessible environment in accordance with codes and standards. The photographs of the picnic area demonstrate that one can have a functionally accessible, code compliant environment but not a universal design. The only accessible picnic tables are located in the parking lot. But this creates isolation and stigma for their users. A universal design approach would have made as many tables as possible fully accessible throughout the main part of the picnic area. Universal design involves social participation as well as function. In fact, this example supports the concept of universal design as an alternative to traditional accessible design. The sign prohibiting use by others demonstrates that the accessible feature of the "reserved" tables were highly desirable by others. Thus, a local ordinance was passed to ensure that people with disabilities could get access to this valuable resource on a priority basis.

Link:
http://secure.cihi.ca/cihiweb/en/downloads/New%20Presentations/ICF%20Presentation%20Notes.pdf

Travers, A. (1991). *Ramps and Rails.*

> This article explains the advantages of ramps and rails.

Link: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1669507/pdf/bmj00122-0041.pdf

York, S. (2009). *Residential Design and Outdoor Area Accessibility.*

> The outdoor environment can provide many positive and therapeutic benefits for persons with complex neurological conditions. In order to benefit from outdoor exposure and experiences, individuals need to be able to access that environment. This article provides a discussion of physical and programmatic access to outdoor living elements in homes and residential facilities for persons with neuro-disabilities. Design considerations for outdoor elements such as common gathering areas, walking paths and paths to/between elements, gardens (viewing and working), and resting areas are presented using legal standards or universal design principles as guides.

Link: http://iospress.metapress.com/content/bk81r4g115p24x38/fulltext.pdf

Women with Disabilities and Health Services

Blanchard, Janice, Susan Hosek. (2005). *Financing Health Care for Women with Disabilities.*

> Women with disabilities, a large and growing segment of the U.S. population, are as a group underserved in primary health care services that are appropriate to their needs. To date, few (if any) formal studies have been done examining the short-term costs or long-term benefits of providing specialized care for these women. This paper describes the major financial issues affecting access to appropriate primary health care for women with disabilities. The assessment is based on a review of the published literature, supplemented by key stakeholder interviews; and covers issues that are relevant at the national level and in southwestern Pennsylvania specifically. The findings and recommendations should be of interest to public and private decision makers seeking to improve access to health care for women with disabilities.

Link: http://www.rand.org/pubs/white_papers/2005/WP139.pdf

Canadian Institute for Health Information. (2003). *Women's Health: A Multi-Dimensional Look at the Health of Canadian Women.*

> This report on the health of Canadian women is intended to: (i) determine the extent to which currently available data can be used to provide gender-relevant insights into women's health; (ii) provide information to support the development of health policy, public health programs, and interventions aimed at improving the health of Canadian women; and (iii) serve as the basis for further indicator development.
>
> The report provides information and descriptive statistics on determinants of health, health status, and health outcomes for Canadian women. To the extent possible, each chapter presents new, gender-relevant information on a health condition or issue identified as important to women's health during national expert and stakeholder consultations in 1999. Where data or appropriate data are lacking, this is documented. Recommendations for change are made at the end of each chapter, accompanied by a discussion of the gaps in and policy implications of the findings.

Link: http://secure.cihi.ca/cihiweb/products/CPHI_WomensHealth_e.pdf

Department for Health and Human Services. (2006). *Access to Health.*

> Good access to health care is particularly important for women with disabilities because they often have other health concerns in addition to their disabilities. Yet women with disabilities face many barriers to care, often simply because people haven't thought about the problems they may encounter. Women with disabilities may not receive regular medical care because of barriers in the physical environment or the attitudes and perceptions of health-care providers.

Link: http://www.cdc.gov/ncbddd/women/access.htm

Meekosha, Helen. (2001). *In/Different Health: Rethinking Gender, Disability and Health.*

> The main argument in this paper is that a central paradox exists when we look at the interconnections between gender, disability and health. We know that disability is not a deficit, not an abnormality to be cured or eliminated, that disability is not incompatible with life's satisfaction, yet disabled women are at higher risk of acquired ill health. We are at high risk of chronic urinary tract infections, major depression, osteoporosis. Most gynaecologists argue that women who use wheel chairs are prime candidates for Osteoporosis and recommend hormone replacement therapy (HRT). But there is little research about the interaction between HRT and our other medications. We are at greater risk of kidney disease, restricted lung disorders, lung disease and heart disease. This is especially so for groups of older women with disabilities (Gill 1996).

Link: http://www.wwda.org.au/indiff.htm

National Coordinating Group on Health Care Reform and Women. (2002). *Women and Health Care Reform.*

> Women are the majority of health care receivers and health care providers in Canada. Approximately 80% of paid health care workers are women. Women provide most of the unpaid health care within the home. During the past decade, federal and provincial governments introduced major changes to the health care system. These health care reforms have a significant impact on women as patients, health care providers, and family caregivers. Health care reforms affect women's health, work and financial well-being.

Link: http://www.womenandhealthcarereform.ca/publications/women-hcren.pdf

Traustadottir, Rannveig. *Women with Disabilities: The Double Discrimination.*

> People with disabilities face many obstacles in their struggle for equality. Although men and women with disabilities are subject to discrimination because of their disabilities, women with disabilities are at a further disadvantage because of the combined discrimination based on disability. This article examines the lives of women with disabilities and explores the effects of this double discrimination.

Link: http://thechp.syr.edu/womdis1.htm

Tudiver, S. & Hall, M. (2005). *Women and Health Care Delivery in Canada.*

> This paper addresses some major issues and current trends pertaining to delivery of health services to women in Canada. A gendered approach to health services is necessary since women make up the majority of health care workers and consumers, and serve as `health guardians' of their families. Women have been in the forefront of those offering substantive critiques of health care delivery in Canada and of the ways women have been excluded from determining major directions in scientific research and practice. Women have urged governments to recognize the importance of social, economic, and other determinants to health, and organized quality services to address population, community and individual health needs.

Link: http://www.hc-sc.gc.ca/hl-vs/pubs/women-femmes/can-usa/can-back-promo_9-eng.php

Turk, Margaret. *Barriers to Health Care for Women with Disabilities: Education of Health Care Providers.*

> The PowerPoint describes the barriers to health care that women experience when attempting to obtain primary health care, gynaecological services, mental health services, dental care, prescriptions, eyeglasses, fitness, etc.

Link: http://www.hhs.gov/od/summit/Turk.ppt#1

Works Cited

1. Abelson, J. and Gauvin, F. (2004). *Transparency, Trust and Citizen Engagement: What Canadians are saying about Accountability*. Retrieved on November 10, 2010, from http://cprn.org/documents/33621_en.pdf

2. Abelson, J. and Gauvin, F. (2006). *Assessing the Impacts of Public Participation: Concepts, Evidence and Policy Implications.* Retrieved on November 10, 2010, from http://www.cprn.org/documents/42669_fr.pdf

3. Access Canada. (2007). *Property Standards Manual – 2007*. Retrieved on March 8, 2010, from http://www.gnb.ca/0048/pcsdp/PDF/PublicationsWebpage/Access%20Canada%20Standards[1].pdf

4. Alberta Committee of Citizens with Disabilities. *Web Site*. Retrieved on March 8, 2010, from http://accd.net/html/what_we_do_projects.html

5. Alberta Employment and Immigration. (2006). *2006 Census Analysis: Persons with Disabilities Profile*. Retrieved on March 8, 2010, from http://employment.alberta.ca/documents/LMI/LMI-LFP_profile_disabilities.pdf

6. Alberta Health and Wellness. (2006). *Alberta Progress on the 10-Year Plan to Strengthen Health Care*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/Strengthen-Health-Care-Progress-2007.pdf

7. Alberta Health and Wellness. (2008). *Vision 2020: The Future of Health Care in Alberta*. Retrieved on March 07, 2010, from http://www.health.alberta.ca/documents/Vision-2020-Phase-1-2008.pdf

8. Alberta Health and Wellness. (2010). *A Foundation for Alberta's Health System: Report of the Minister's Advisory Committee on Health*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/MACH-Final-Report-2010-01-20.pdf

9. Alberta Health and Wellness. (2010). *Annual Report 2009-2010*. Retrieved on February 28, 2011, from http://www.health.alberta.ca/documents/Annual-Report-10.pdf

10. Alberta Health and Wellness. (2010). *Health Coverage and Funding Quick Facts 2010*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/newsroom/funding-quick-facts.html

11. Alberta Health and Wellness. (2010). *Putting People First: A Summary of Albertans' Views*. Retrieved on November 8, 2010, from http://www.health.alberta.ca/documents/Alberta-Health-Act-Summary-2010.pdf

12. Alberta Health and Wellness. (2010). *Putting People First: Recommendations for an Alberta Health Act*. Retrieved on September 28, 2010, from http://www.health.alberta.ca/documents/Alberta-Health-Act-Report-2010.pdf

13. Alberta Health Services. (2008). *Demographics: Demographic Information of Diverse Populations.* Retrieved on March 07, 2010, from http://www.calgaryhealthregion.ca/programs/diversity/demographics/demographics_of_div_pop.pdf

14. Alberta Health Services. (2008). *Persons with Disabilities: Health Services Literature Review and Community Consultations*. Retrieved on March 07, 2010, from http://www.calgaryhealthregion.ca/programs/diversity/diversity_resources/research_publications/disabilities_report.pdf

15. Alberta Health Services. (2009). *Strategic Direction 2009-2010: Defining Our Focus/Measuring Our Progress*. Retrieved on March 07, 2010, from http://www.albertahealthservices.ca/files/org-strategic-direction.pdf

16. Alberta Human Rights Commission. *Alberta Human Rights Act*. Retrieved on March 07, 2010, from http://www.albertahumanrights.ab.ca/services/medical/faqs.asp

17. Alberta Human Rights Commission. *Web Site*. Retrieved on March 07, 2010, from http://www.albertahumanrights.ab.ca/Bull_DutytoAccom_web.pdf

18. Alberta Rural Physician Action Plan. (2005). *Evaluation of the Alberta Rural Physician Action Plan: Final Report*. Retrieved on September 1, 2010, from http://www.rpap.ab.ca/pdf/2005_RPAP_Evaluation_Final_Report_9Aug2005.pdf

19. Alberta Seniors and Community Supports. (2006). *A Profile of Albertans with Disabilities: a Compilation of Information from National Data Sources*. Retrieved on March 8, 2010, from

http://www.assembly.ab.ca/lao/library/egovdocs/2006/als/164878.pdf

20. Armitage, G. et al. (2009). Health Systems Integration: State of the Evidence. *International Journal of Integrated Care – Vol. 9, 17 June 2009*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2707589/pdf/ijic2009-200982.pdf

21. Audas, R., Ryan, A. and Vardy, D. (2009). *Where Did the Doctors Go? A Study of Retention and Migration of Provisionally Licensed International Medical Graduates Practising in Newfoundland and Labrador between 1995 and 2006*. Retrieved on September 1, 2010, from http://www.cma.ca/multimedia/staticContent/HTML/N0/l2/cjrm/vol-14/issue-1/pdf/pg21.pdf

22. Augmentative and Alternative Communication Community Partnerships-Canada. (2009). *Communication Access for People who have Communication Disabilities: Guidelines and Resources on Communication with People who Have Communications Disabilities*. Retrieved on March 8, 2010, from http://www.accesson.ca/documents/en/mcss/accessibility/DevelopingStandards/Communication_Access_ENG_no_ack.pdf

23. Bachman, S. et al. (2006). *Provider Perceptions of Their Capacity to Offer Accessible Health Care for People with Disabilities*. Retrieved on March 8, 2010, from http://www.questia.com/read/5018547466?title=Provider%20Perceptions%20of%20Their%20Capacity%20to%20Offer%20Accessible%20Health%20Care%20for%20People%20with%20Disabilities

24. Benner, P. (2004). Seeing the Person Beyond the Disease. *American Journal of Critical Care. January 2004, Volume 13*. Retrieved on March 8, 2010, from http://ajcc.aacnjournals.org/cgi/reprint/13/1/75

25. Berube, B. (1981). Barrier-Free Design – Making the Environment Accessible to the Disabled. *CMA Journal, January 1, 1981, Volume 124*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1705088/pdf/canmedaj01473-0070.pdf

26. BioInfoBank Library. *Web Site*. Retrieved on May 15, 2010, from http://lib.bioinfo.pl/home/about

27. Bowers, B., Esmond, S., Lutz, B. and Jacobson, N. (2003). Improving Primary Care for Persons with Disabilities: the nature of expertise.

Disability & Society, Vol. 18, No. 4, 2003, pp. 443–455. Retrieved on March 8, 2010, from http://www.dhs.wisconsin.gov/wipartnership/pdf-wpp/appe.pdf

28. Branigan, M. et al. (2001). Perceptions of Primary health care Services among Persons with Physical Disabilities. Part 2: Quality Issues. *Medscape General Medicine. 2001; 3(2)*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/408123

29. Brathwaite, D. and Thompson, T. (ed). (2002). *Handbook of Communication and People with Disabilities: Research and Application*. Retrieved on March 8, 2010, from http://www.questia.com/read/28054019?title=Handbook%20of%20Communication%20and%20People%20with%20Disabilities%3a%20Research%20and%20Application

30. Brawely, Elizabeth. (2009). Enriching Lighting Design. *NeuroRehabilitation 25 (2009) 189–199*. Retrieved on March 8, 2010, from http://iospress.metapress.com/content/t5151v545346x40l/fulltext.pdf

31. British Columbia Ministry of Health. (2007). *2007/08-2009/10 Service Plan*. Retrieved on October 8, 2010, from, http://www.bcbudget.gov.bc.ca/2007/sp/pdf/ministry/hlth.pdf

32. Bruni, R., Laupacis, A. and Martin, D. Public Engagement in Setting priorities in Health Care. *Canadian Medical Association Journal. July 1, 2008: 179(1)*. Retrieved on November 10, 2010, from http://www.cmaj.ca/cgi/reprint/179/1/15

33. Bruns, Bryan. (2003). *Water Tenure Reform: Developing an Extended Ladder of Participation*. Retrieved on November 10, 2010, from http://www.bryanbruns.com/bruns-ladder.pdf

34. Canada Department of Justice. *Canadian Charter of Rights and Freedoms*. Retrieved on March 8, 2010, from http://laws.justice.gc.ca/en/charter/

35. Canada Department of Justice. *Canadian Human Rights Act (R.S., 1985, c. H-6)*. Retrieved on March 8, 2010, from http://laws.justice.gc.ca/en/H-6/index.html

36. Canada Health. (2001). *Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada*. Retrieved on September 28, 2010, from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-certain-equit-acces/2001-certain-equit-acces-eng.pdf

37. Canada Transportation Act Review Panel. (2001). *Vision and Balance: Report of the Canada Transportation Act Review Panel*. Retrieved on March 8, 2010, from http://www.reviewcta-examenltc.gc.ca/english/pages/final/tablee.htm

38. Canadian Health Services Research Foundation. (2003). *Choices for Change: The Path for Reconstructing Primary health care Services in Canada*. Retrieved on September 28, 2010, from http://www.chsrf.ca/final_research/commissioned_research/policy_synthesis/pdf/choices_for_change_e.pdf

39. Canadian Human Rights Commission. *Duty to Accommodate*. Retrieved on March 10, 2010, from http://www.chrc-ccdp.ca/portal_portail/duty_obligation-en.asp

40. Canadian Institute for Health Information. (2005). *Geographic Distribution of Physicians in Canada: Beyond How Many and Where*. Retrieved on September 1, 2010, from http://secure.cihi.ca/cihiweb/products/Geographic_Distribution_of_Physicians_FINAL_e.pdf

41. Canadian Institute for Health Information. (2006). *Medical Imaging Technologies in Canada, 2006—Supply, Utilization and Sources of Operating Funds*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/products/mit_analysis_in_brief_e.pdf

42. Canadian Institute for Health Information. (2009). *National Health Expenditure Trends, 1975 to 2009*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/products/National_health_expenditure_trends_1975_to_2009_en.pdf

43. Canadian Institute for Health Information. (2009). *Supply, Distribution and Migration of Canadian Physicians, 2008*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/products/SMDB_2008_e.pdf

44. Canadian Institute for Health Information. *Web Site*. Retrieved May 15, 2010, from http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=services_e

45. Casebeer, A. and Reay, T. (2004). Reinventing Primary Health Care: Physicians Have a Pivotal Part to Play. *Canadian Family Physician VOL 50: OCTOBER*. Retrieved on September 28, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2214508/pdf/1552686.pdf

46. Chew, K., Iacono, T. and Tracy, J. 2009). Overcoming Communication Barriers: Working with Patients with Intellectual Disabilities. *Australian Family Physician Vol. 30, January/February 2009*. Retrieved on March 8, 2010, from http://www.racgp.org.au/afp/200901/200901chew.pdf

47. Clow, B., Pederson, A. Haworth-Brockman, M. and Bernier, J. (2009). *Rising to the Challenge: Sex- and Gender-Based Analysis for Health Planning, Policy and Research in Canada*. Retrieved on March 8, 2010, from http://www.pwhce.ca/pdf/RisingToTheChallenge.pdf

48. College of Physicians and Surgeons of Ontario. (2008). *Physicians and the Ontario Human Rights Code: Policy Statement #5-08*. Retrieved on March 8, 2010, from http://www.cpso.on.ca/uploadedFiles/downloads/cpsodocuments/policies/policies/human_rights.pdf

49. Commission on the Future of Health Care in Canada. (2002). *Access to health care in Canada*. Retrieved on March 8, 2010, from http://www.chsrf.ca/other_documents/romanow/pdf/accesstocare_e.pdf

50. Commission on the Future of Health Care in Canada. (2002). *Report on Citizens' Dialogue on the Future of Health Care in Canada*. Retrieved on March 8, 2010, from http://www.cprn.org/documents/12704_en.PDF

51. *Council of Canadians with Disabilities vs. Via Rail Canada Inc*. Retrieved on March 8, 2010, from http://scc.lexum.umontreal.ca/en/2007/2007scc15/2007scc15.html

52. Council of Canadians with Disabilities. (2008). *A Disability Rights Analysis of Canada's Record Regarding the Human Rights of Persons with Disabilities: A Submission by CCD to the Human Rights Council in Relation to the 2009 Periodic Review of Canada*. Retrieved on March 8, 2010, from http://www.ccdonline.ca/en/humanrights/promoting/periodic-review-2009

53. Council of Canadians with Disabilities. (2008). *CCD Wins Removal of Longstanding Barrier to Mobility and Travel*. Retrieved on March 8, 2010, from http://www.ccdonline.ca/en/transportation/air/no-surcharge-extra-inflight-seat

54. Crichton, A., Robertson, A., Gordon, C. and Farrant, W. (1997). *Health Care: A Community Concern? Developments in the Organization of Canadian Health Services*. Retrieved on March 8, 2010, from http://www.questia.com/read/102576070?title=Health%20Care%3a%20A%20Community%20Concern%3f

55. Department of Health and Community Services (Newfoundland and Labrador). (2011). *Annual Performance Report 2009-2010*. Retrieved on October 09, 2010, from, http://www.health.gov.nl.ca/health/publications/2009_2010_DHCS_Annual_Report_Tabled_Final.pdf

56. Department of Health and Wellness Prince Edward Island. *Web Site*. Retrieved on October 8, 2010, from, http://www.gov.pe.ca/health/index.php3?number=1025090&lang=E

57. Department of Health Prince Edward Island. (2008). *Department of Health Annual Report 2007-2008*. Retrieved on October 8, 2010, from, http://www.gov.pe.ca/photos/original/doh.pdf

58. Detsky, A. and Naylor, D. (2003). Canada's Health Care System – Reform Delayed. *The New England Journal of Medicine 349; 8 August 21, 2003*. Retrieved on March 8, 2010, from, http://www.gdctn.org/info/HealthCare/Canada%20Reform%20Delayed-%20NEJM%202003.pdf

59. Di Matteo, L. and Di Matteo, R. (2009). *The Fiscal Sustainability of Alberta's Public Health Care System*. Retrieved on September 28, 2010, from http://policyschool.ucalgary.ca/files/publicpolicy/diMatteo%20ONLINE%20(Apr%2009).pdf

60. *Disability Rights Council et al. v. Washington Hospital Center*. Retrieved on March 8, 2010, from http://www.ada.gov/whc.htm

61. Donabedian, Avedis. (2005). Evaluating the Quality of Medical Care. *The Milbank Quarterly, Vol. 83, No. 4, 2005 (pp. 691–729)*. Retrieved on March 8, 2010, from www.milbank.org/quarterly/830416donabedian.pdf

62. Elliot, H. and Popay, Jennie. (2000). How are Policy makers Using Evidence? Models of Research Utilisation and Local NHS Policy Making. *J Epidemiol Community Health 2000; 54:461–468*. Retrieved on September 15, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1731692/pdf/v054p00461.pdf

63. Entrex. *Web Site*. Retrieved on May 15, 2010, from http://www.ncbi.nlm.nih.gov/gquery/gquery.fcgi

64. Evans, Robert. (2007). *Economic Myths and Political Realities: The Inequality Agenda and the Sustainability of Medicare*. Retrieved on

September 28, 2010, from http://www.chspr.ubc.ca/files/publications/2007/chspr07-13W.pdf

65. Federal Ministry of Food, Agriculture and Consumer Protection. (2008). *Innovative Service Delivery: Meeting the Challenges of Rural Regions.* Retrieved on September 1, 2010, from http://www.oecd.org/dataoecd/14/42/41063088.pdf

66. Feldman, K., Woloschuk, W., Gowans, M., Delva, D., Brenneis, F., Wright, B., and Scott, I. (2008). The Difference between Medical Students Interested in Rural Family Medicine versus Urban Family or Specialty Medicine. *Canadian Journal of Rural Medicine 2008; 13(2): 73-9*. Retrieved on September 1, 2010, from http://www.cma.ca/index.php/ci_id/85634/la_id/1/print/true.htm

67. Francis, L. and Silvers, A. (2008). *Debilitating Alexander V. Choate: "Meaningful Access" to Health Care for People with Disabilities*. Retrieved on March 8, 2010, from http://www.questia.com/read/5027722057?title=Debilitating%20Alexander%20V.%20Choate%3a%20%22Meaningful%20Access%22%20to%20Health%20Care%20for%20People%20with%20Disabilities

68. Gerschick, T. J. (2000). Toward a Theory of Disability and Gender. *Signs, 25(4), 1263*.

69. *Gillespie, et al. v. Laurel Regional Hospital*. Retrieved on March 8, 2010, from http://thebarrierfreehealthcareinitiative.org/?page_id=16

70. Glazier, Richard. (2007). Balancing Equity Issues in Health Systems: Perspectives of Primary health care. *Healthcare Papers, 8(Sp) 2007: 35-45*. Retrieved on September 28, 2010, from http://www.longwoods.com/content/19218

71. Government of Canada. (2003). *Defining Disability: A Complex Issue*. Retrieved on March 8, 2010, from http://dsp-psd.communication.gc.ca/Collection/RH37-4-3-2003E.pdf

72. Government of Canada. (2004). *A 10-Year Plan to Strengthen Health Care*. Retrieved on March 8, 2010, from, http://www.scics.gc.ca/cinfo04/800042005_e.pdf

73. Government of Canada. (2008). *2008 Federal Disability Report*. Retrieved on September 28, 2010, from http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2008/fdr_2008.pdf

74. Government of Canada. (2009). *2009 Federal Disability Report*. Retrieved on September 28, 2010, from http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2008/fdr_2008.pdf

75. Government of Canada. (2010). *Canada Health Act*. Retrieved on March 8, 2010, from, http://laws.justice.gc.ca/PDF/Statute/C/C-6.pdf

76. Government of Manitoba. (2008). *Manitoba Budget 2008*. Retrieved on October 8, 2010, from, http://www.gov.mb.ca/finance/budget08/papers/budget.pdf

77. Health Canada. (2001). *Certain Circumstances: Issues in Equity and Responsiveness in Access to Health Care in Canada*. Retrieved on September 28, 2010, from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-certain-equit-acces/2001-certain-equit-acces-eng.pdf

78. Health Canada. (2009). *Canada Health Act – Annual Report 2008-2009*. Retrieved on March 8, 2010, from, http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/cha-ics/2209-cha-ics-ar-ra/chaar-ralcs-09-eng.pdf

79. Health Quality Council of Alberta. (2010). *Satisfaction and Experience with Health Care Services: A Survey of Albertans 2010*. Retrieved on December 26, 2010, from http://www.hqca.ca/assets/pdf/Surveys/HQCA_SE_Technical_Report_2010.pdf

80. Health Technology Assessment Task Group. *Health Technology Strategy 1.0 Final Report, 2004*. Retrieved on September 28, 2010, from http://www.cadth.ca/media/policy_forum_section/1_health_tech_strategy_1.0_nov-2004_e.pdf

81. Herbert, R. (2007). Canada's Health Care Challenge: Recognizing and Addressing the Health Needs of Rural Canadians. Lethbridge *Undergraduate Research Journal, 2007, Volume 2 Number 1*. Retrieved on September 1, 2010, from http://www.uleth.ca/dspace/bitstream/10133/495/1/Herbert.pdf

82. Hogg, J. (2001). Essential health care for People with Learning Disabilities: Barriers and Opportunities. *Journal of the Royal Society of Medicine 2001 July; 94(7): 333–336*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1281596/

83. Howe, T. and Worrall, L. (2006). *Environmental Factors and People with the Language Disorder of Aphasia*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/en/downloads/Tami%20Howe%20-%20Oral%20Health%20&%20the%20Environment.pdf

84. Human Resources and Skill Development Canada. (2007) *Addressing the Challenges and Opportunities of Ageing in Canada*. Retrieved on March 8, 2010, from http://www.hrsdc.gc.ca/eng/publications_resources/research/categories/population_aging_e/madrid/madride.pdf

85. Human Resources and Skills Development Canada. (2009). *Advancing the Inclusion of People with Disabilities: 2009 Federal Disability Report*. Retrieved on March 8, 2010, from http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2009/fdr_2009.pdf

86. Human Resources and Skills Development Canada. (2006). *Indicators of Well-being in Canada: Canadians in Context – People with Disabilities*. Retrieved on July 25, 2010, from http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=40

87. Human Resources and Skills Development. (1999). *Future directions To Address Disability Issues for the Government of Canada: Working Together for Full Citizenship*. Retrieved on March 8, 2010, from http://www.servicecanada.gc.ca/eng/cs/sp/sdc/socpol/publications/reports/1999-000046/page08.shtml

88. Iezzoni, L. (2003). Targeting Health Care Improvement for People with Disabilities. *International Journal for Quality in Health Care 2003: Volume 15, Number 4, pp. 279-281*. Retrieved on September 28, 2010, from http://intqhc.oxfordjournals.org/content/15/4/279.full.pdf+html

89. Iezzoni, L., Davis, R., Soukup, J. and O'Day, B. (2003). Quality Dimensions That Most Concern People With Physical and Sensory Disabilities. *ARCH INTERN MED/VOL 163, SEP 22, 2003*. Retrieved on March 8, 2010, from http://archinte.ama-assn.org/cgi/reprint/163/17/2085

90. Institute for Clinical Evaluative Sciences. (2009). *What Does it Take to Make a Healthy Province? A Benchmark Study of Jurisdictions in Canada and Around the World with the Highest Levels of Health and the Best Health Behaviours: ICES Investigative Report.* Retrieved on September 28, 2010, from http://www.ices.on.ca/file/Healthy%20province%20November%20release.pdf

91. Institute of Law and Research and Reform. (1989). *Competence and Human Reproduction*. Retrieved on March 8, 2010, from http://www.law.ualberta.ca/alri/docs/fr52.pdf

92. Issaacson Kailes, J. and Mac Donald, C. (2009). *Importance of Accessible Examination Tables, Chairs and Weight Scales*. Retrieved on March 8, 2010, from http://www.cdihp.org/briefs/1%20%20Brief-Exam%20Tables%20and%20Scales-FINAL%20Edition%204_4%208%2009.pdf

93. Joines, S. (2009). Enhancing Quality of Life through Universal Design. *NeuroRehabilitation. 2009; 25 (3):155-67*. Retrieved on March 8, 2010, from http://iospress.metapress.com/content/5g112p283123h141/fulltext.html

94. Jones, K. and Tamari, I. (1997). Making Our Offices Universally Accessible: Guidelines for Physicians. *Can Med Assoc J 1997; 156:647-56*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1232828/pdf/cmaj_156_5_647.pdf

95. Jongbloed, Lyn. (2003). Disability Policy in Canada: An Overview. *Journal of Disability Policy Studies. Volume: 13. Issue: 4. Publication Year: 2003*. Page Number: 203+. Retrieved on March 8, 2010, from http://www.questia.com/read/5001705967?title=Disability%20Policy%20in%20Canada%3a%20An%20Overview

96. Kluge, Eike-Henner. (2007). Comparing health care Systems: Outcomes, Ethical Principles, and Social Values. *Medscape General Medicine. 2007; 9(4):29*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/564144

97. Kluge, Eike-Henner. (2007). Resource Allocation in health care: Implications of Models of Medicine as a Profession. *Medscape General Medicine. 2007; 9(1):57*. Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/551802

98. Laurent, Stephen. (2002). *Rural Canada: Access to Health Care*. Retrieved on September 1, 2010, from http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/prb0245-e.htm

99. Leatherman, S. and Sutherland, K. (2010). *Quality of health care in Canada: A Chartbook*. Retrieved on September 28, 2010, from http://www.chsrf.ca/pdf/chartbook/CHARTBOOK%20Eng_June_withdate.pdf

100. Lepofsky, D., and Graham, R. *Universal Design in Legislative Drafting – How to Ensure Legislation is Barrier-Free for People with Disabilities*. Retrieved on March 8, 2010, from http://www.crvawc.ca/documents/Universal%20design%20in%20drafting%20barrier%20free%20legislation%20for%20people%20with%20disabilities.pdf

101. Lewis, S., Donaldson, C., Mitton, C. and Currie, G. (2001). The Future of Health Care in Canada. *British Medical Journal 2001; 323:926–9*. Retrieved on March 8, 2010, from, http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121447/pdf/926.pdf

102. Litman, Todd. (2003). *Social Inclusion As A Transport Planning Issue in Canada: Contribution To The FIA Foundation G7 Comparison*. Retrieved on March 8, 2010, from http://www.vtpi.org/soc_ex.pdf

103. Mack, Kelly. (2005). Accessible Medical Exam Tables: Just Ask. Retrieved on March 8, 2010, from http://www.equalizers.org/issues/New_Mobility_Dec05.pdf

104. MacKinnon, M., Maxwell, J., Rosell, S. and Saxena, N. (2003). *Citizens' Dialogue on Canada's Future: A 21st Century Social Contract*. Retrieved on March 8, 2010, from http://www.owr.ca/19110_en.pdf

105. Manfredi, C. and Maioni, A. (2005). *Litigating Innovation: Health Care Policy and the Canadian Charter of Rights and Freedoms*. Retrieved June 15, 2010, from http://www.cpsa-acsp.ca/papers-2005/Manfredi.pdf

106. Manitoba Health and Healthy Living. (2008). *Annual Report 2008-2009*. Retrieved on October 8, 2010, from, http://www.gov.mb.ca/health/ann/docs/0809.pdf

107. Marc Lee. (2007). *How Sustainable is Medicare? A Closer Look at Aging, Technology and Other Cost Drivers in the Canada's Health Care System*. Retrieved on March 8, 2010, from http://www.policyalternatives.ca/sites/default/files/uploads/publications/National_Office_Pubs/2007/How_Sustainable_is_Medicare.pdf

108. Marks, M. and Teasell, R. (2006). More than Ramps: Accessible Health Care for People with Disabilities. *CMAJ. 2006 August 15; 175(4): 329*. Retrieved on March 8, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1534102/?tool=pubmed

109. MASS LBP. (2009). *Engaging with Impact: Targets and Indicators for Successful Community Engagement by Ontario's Local Health Integration Networks: A Citizens' Report from Kingston, Richmond Hill and Thunder Bay*. Retrieved on March 8, 2010, from http://www.masslbp.com/media/engagingreport.pdf

110. McColl, M., Forster, D., Shortt, S., Hunter, D., Dorland, J., Godwin, M. and Rosser, W. (2008). Physician Experiences Providing Primary Care to People with Disabilities. *Healthcare Policy, 4(1) 2008: e129-e147*. Retrieved on March 8, 2010, from http://www.longwoods.com/content/19989

111. *McKay-Panos v. Air Canada*. Retrieved on March 8, 2010, from http://www.schenklaw.ca/resource/mackay.htm

112. McKinlay, Eileen. (2005). *Men and Health: A Literature Review*. Retrieved on September 1, 2010, from http://www.phac.health.govt.nz/moh.nsf/pagescm/766/$File/mens-health-literature-review.pdf

113. Mechanic, D. (2002). *Removing Barriers to Care among Persons with Psychiatric Symptoms*. Retrieved on September 28, 2010, from http://content.healthaffairs.org/cgi/reprint/21/3/137

114. Medscape. *Web Site*. Retrieved May 15, 2010, from http://www.medscape.com/public/about

115. Meekosha, Helen. (2004). *Gender and Disability*. Retrieved on March 8, 2010, from http://www.wwda.org.au/meekoshagendis1.pdf

116. Minnesota Department of Health. (2002). *Strategies for Public Health: A Compendium of Ideas, Experience, and Research from Minnesota's Public Health Professionals*. Retrieved on March 8, 2010, from http://www.health.state.mn.us/strategies/engagement.pdf

117. Mitton, C., Smith, N., Peacock, S., Evoy, B. and Abelson, J. (2009). Public Participation in Health Care Priority Setting: A Scoping Review. *Health Policy 91 (2009) 219–228*. Retrieved on March 8, 2010, from http://www.canprep.ca/library/Public_Participation_in_Priority_Setting.pdf

118. Morgan, M., Zamora, N. and Hindmarsh, M. (2007). *An Inconvenient Truth: A Sustainable Health Care System Requires Chronic Disease Prevention and Management Transformation*. Retrieved on March 8, 2010, from

http://www.northwestlhin.on.ca/uploadedFiles/Home_Page/Integrated_Health_Service_Plan/An%20Inconvenient%20Truth.pdf

119. Morris, R. (1965). *Next Steps in Removing Barriers to Health Care*. Retrieved on September 28, 2010, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1750845/pdf/bullnyacadmed00285-0086.pdf

120. Mudrick, N. and Yee, S. (2007). *Defining Programmatic Access to health care for People with Disabilities*. Retrieved on March 8, 2010, from http://www.dredf.org/healthcare/Healthcarepgmaccess.pdf

121. National Disability Authority. (2006). *Literature Review on Attitudes towards Disability*. Retrieved on September 25, 2010, from http://issda.ucd.ie/documentation/nda/nda06-literature.pdf

122. National Library of Medicine. *Web Site*. Retrieved May 15, 2010, from http://www.nlm.nih.gov/pubs/factsheets/medline.html

123. National Research Council of Canada. *A Brief History of Canada's National Codes*. Retrieved May 15, 2010, from http://www.google.ca/search?sourceid=chrome&ie=UTF-8&q=History+of+Canada's+National+Building+Code

124. New Brunswick Department of Health. (2009). *2008-2009 Annual Report*. Retrieved on October 8, 2010, from, http://www.gnb.ca/0051/pub/pdf/6698ef.pdf

125. New Brunswick Health and Wellness. (2004). *Healthy Futures: Securing New Brunswick's Health Care System – The Provincial Health Plan 2004-2008*. Retrieved on October 8, 2010, from, http://www.gnb.ca/0051/pdf/healthplan-2004-2008_e.pdf

126. North Carolina Office on Disability and Health. *Partners in health care*. Retrieved on March 8, 2010, from http://www.fpg.unc.edu/~ncodh/pdfs/partners.pdf

127. Northwest Territories Health and Social Services. *Web Site*. Retrieved on October 8, 2010, from, http://www.hlthss.gov.nt.ca/english/our_system/about_us/hss_department.htm

128. Northwest Territories Ministry of Finance. *Web Site*. Retrieved on October 8, 2010, from, http://www.fin.gov.nt.ca/address/index.htm

129. Nova Scotia Department of Health. (2009). *Annual Accountability Report for the Fiscal Year 2009-2010*. Retrieved on October 8, 2010, from, http://www.gov.ns.ca/health/reports/pubs/DOH_Accountability_2009_10.pdf

130. Nova Scotia Department of Health. (2010). *2010-2011 Statement of Mandate*. Retrieved on October 8, 2010, from, http://www.gov.ns.ca/health/reports/pubs/DOH_Statement_of_Mandate_2010_2011.pdf

131. Nunavut Health and Social Services. *Web Site*. Retrieved on October 8, 2010, from, http://www.gov.nu.ca/health/

132. Office of Rural and Northern Health. *From Rural High School to Rural Practice*. Retrieved on October 8, 2010, from, http://www.ornh.mb.ca/docs/edu_to_sust.pdf

133. Ontario Human Rights Commission. (2000). *Submission of the Ontario Human Rights Commission to the College of Physicians and Surgeons of Ontario Regarding the draft policy, "Physicians and the Ontario Human Rights Code."* Retrieved on March 8, 2010, from http://www.ohrc.on.ca/en/resources/submissions/physur?page=suben-Contents.html

134. Ontario Ministry of Health and Long-Term Care. *Web Site*. Retrieved on October 8, 2010, from, http://www.health.gov.on.ca/en/ministry/default.aspx

135. Ontario Ministry of Health and Long-Term Care. (2009). *2009-2010 Accessibility Plan*. Retrieved on October 8, 2010, from, http://www.health.gov.on.ca/en/public/publications/aplans/aplan10/aplan10.pdf

136. Ontario Ministry of Municipal Affairs and Housing. (2004). *Strong Rural Communities: Working Together for Success Ontario's Rural Plan.* Retrieved on September 1, 2010, from http://www.omafra.gov.on.ca/english/rural/rural_plan/rp06heal.htm

137. Prairie Women's Health Centre of Excellence. (2003). *Including Gender in Health Planning: A Guide for Regional Health Authorities*. Retrieved on March 8, 2010, from http://www.pwhce.ca/pdf/gba.pdf

138. Pritzlaff, C., Cesar, K., Tymus, T. and Fiedler, I. (2002). Perceived Versus Actual Physical Accessibility of Substance Abuse Treatment Facilities. *Top Spinal Cord Inj Rehabil 2002; 7(3):47–55*. Retrieved on September 29,

2010, from
http://thomasland.metapress.com/content/tv0rt8tle3j57k2l/fulltext.pdf

139. PubMed. *Web Site*. Retrieved on May 15, 2010, from http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=helppubmed&part=pubmedhelp#pubmedhelp.FAQs

140. Rogow, Sally. *The Disability Rights Movement: The Canadian Experience*. Retrieved on March 25, 2011, from http://www.internationalsped.com/magazines_articles/The%20Disability%20Rights%20Movement%20Ed.1.pdf

141. Roush, Susan. (1986). Health Professionals as Contributors to Attitudes towards Persons with Disabilities: A Special Communication. *Physical Therapy Volume 66/November 10, October 1986*. Retrieved on March 8, 2010, from http://ptjournal.apta.org/content/66/10/1551.full.pdf

142. Safety Codes Council. (2008). *Design for Independence and Dignity for Everyone: Vision, Hearing, Communication, Mobility, Cognition – barrier-Free Design Guide*. Retrieved on September 10, 2010, from http://www.safetycodes.ab.ca/upload/docs/SCC-BFDG-FINAL-protected.pdf

143. Sanmartin, C. and Ross, N. (2006). Experiencing Difficulties Accessing First-Contact Health Services in Canada. *Healthcare Policy, 1(2): 103-119*. Retrieved on September 29, 2010, from http://www.longwoods.com/content/17882

144. Saskatchewan Ministry of Health. *Plan for 2010-2011*. Retrieved on October 8, 2010, from, http://www.finance.gov.sk.ca/PlanningAndReporting/2010-11/HealthPlan1011.pdf

145. Scheer, J.; Kroll, T.; Neri, M.T.; and Beatty, P. (2003). Access Barriers for Persons with Disabilities: The Consumer's Perspective. *Journal of Disability Policy Studies, 13(4): 221-230*. Retrieved on September 29, 2010, from http://www.worksupport.com/resources/viewContent.cfm/235

146. Shakespeare, T. (1999). The Sexual Politics of Disabled Masculinity. *Sexuality and Disability, 17(1), 53-64*. Retrieved on September 29, 2010, http://www.springerlink.com/content/k472p3858472w062/

147. Shuttleworth, R. P. (2004). Disabled Masculinity: Expanding the Masculine Repertoire. *In B. Hutchinson & B. G. Smith (Eds.), Gendering disability (pp. 166-178).* Retrieved on September 29, 2010,

http://books.google.ca/books?hl=en&lr=&id=pUBsk629Sr8C&oi=fnd&pg=PA166&dq=Disabled+masculinity:+Expanding+the+masculine+repertoire.&ots=UG1W-tfgcC&sig=j_d2A9lEyn0LvxDm6t2FrlMGpIU#v=onepage&q=Disabled%20masculinity%3A%20Expanding%20the%20masculine%20repertoire.&f=false

148. Skinner, B. and Roevere, M. (2009). *Paying More, Getting Less: Measuring the Sustainability of Government Health Spending in Canada*. Retrieved on September 28, 2010, from http://www.fraseramerica.org/commerce.web/product_files/PayingMoreGettingLess2009_US.pdf

149. Smith, James. (2007). Addressing Men's Health policy Concerns in Australia: What Can be Done? *Australia and New Zealand Health Policy 2007, 4:20 doi: 10.1186/1743-8462-4-20*. Retrieved on September 1, 2010, from http://www.anzhealthpolicy.com/content/pdf/1743-8462-4-20.pdf

150. Spinal Cord Injury Solutions Network. (2008). *A Scoping Review of Disability Policy in Canada: Effects on Community Integration for People with Spinal Cord Injuries*. Retrieved on March 8, 2010, from http://chspr.queensu.ca/downloads/Reports/Disability%20Policy%20in%20Canada-final%20report-May09.pdf

151. Statistics Canada. (2001). *A Profile of Disability in Canada, 2001*. Retrieved on March 8, 2010, from http://www.rhdcc.gc.ca/eng/cs/sp/sdc/pkrf/publications/research/2001-000123/89-577-XIE01001.pdf

152. Statistics Canada. (2005). *Access to Health Care Services in Canada*. Retrieved on March 8, 2010, from http://www.statcan.gc.ca/pub/82-575-x/82-575-x2006002-eng.pdf

153. Statistics Canada. (2009). *Canadian Community Health Survey 2008*. Retrieved on March 8, 2010, from http://www.statcan.gc.ca/daily-quotidien/090626/dq090626b-eng.htm

154. Statistics Canada. *Participation and Activity Limitation Survey 2006: Analytical Report.* Retrieved on March 8, 2010, from http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.pdf

155. *Stein v Québec (Régie de l'Assurance-maladie), [1999] QJ No 1241 (Que SC, March 28, 2000)*. Retrieved on March 8, 2010, from http://www.cdhowe.org/pdf/commentary_164.pdf

156. Steinfeld, E. and Danford, S. (2006). *Universal Design and the ICF*. Retrieved on March 8, 2010, from http://secure.cihi.ca/cihiweb/en/downloads/New%20Presentations/ICF%20Presentation%20Notes.pdf

157. Strasser, Roger. (2010). Community Engagement: A Key to Successful Rural Clinical Education. *Rural and Remote Health 10: 1543. (Online), 2010*. Retrieved on November 10, 2010, from http://www.rrh.org.au/publishedarticles/article_print_1543.pdf

158. Sullivan, W., J, J. Heng, D. Cameron, Y. Lunsky, T. Cheetham, B. Hennen, E. Bradley, J. M. Berg, M. Korossy, C. Forster-Gibson, M. Gitta, C. Stavrakaki, B. McCreary, I. Swift. 2006. Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities. *Canadian Family Physician 52: 1410-18*. Retrieved on November 10, 2010, from http://www.cfpc.ca/cfp/2006/Nov/_pdf/vol52-nov-cme-sullivan.pdf

159. Supreme Court of Canada. *Chaoulli v. Quebec (Attorney General).* Retrieved June 15, 2010, from http://csc.lexum.umontreal.ca/en/2005/2005scc35/2005scc35.html

160. Supreme Court of Canada. *Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624*. Retrieved June 15, 2010, from http://scc.lexum.umontreal.ca/en/1997/1997scr3-624/1997scr3-624.html

161. Tepper, M. S. (1999). Letting Go of Restrictive Notions of Manhood: Male Sexuality, Disability and Chronic Illness. Sexuality *and Disability, 17(1), 37-52*. Retrieved on March 8, 2010, from http://www.springerlink.com/content/q8142423xg454355/

162. The Clinics of North America. *Web Site*. Retrieved on May 15, 2010, from http://www.theclinics.com/

163. The Government of Alberta. (2000). *Health Care Protection Act*. Retrieved on March 8, 2010, from http://www.qp.alberta.ca/574.cfm?page=H01.cfm&leg_type=Acts&isbncln=9780779724987

164. The Government of Prince Edward Island. (2007). *Master Agreement between the Medical Society of Prince Edward Island and the Government of Prince Edward Island: April 1, 2007-March 31, 2010*. Retrieved on October 8, 2010, from, http://www.gov.pe.ca/photos/original/doh_masteragree.pdf

165. The Ministère de la Santé et des Services sociaux. *Web Site*. Retrieved on October 8, 2010, from, http://www.msss.gouv.qc.ca/sujets/organisation/ssss_enbref/index.php?repartition_budgetaire_en

166. The Ministère de la Santé et des Services sociaux. (2006). *Annual Management Report 2005-2006*. Retrieved on October 8, 2010, from, http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-102-01.pdf

167. Trillium Health Centre. (2004). *Creating a Barrier-Free World: Annual Accessibility Plan 2004-2005*. Retrieved on March 8, 2010, from http://www.trilliumhealthcentre.org/about/AccessibilityPlan2004_05_v2.pdf

168. Tudiver, S. and Hall, M. (2005). *Women and Health Care Delivery in Canada*. Retrieved on March 8, 2010, from http://www.hc-sc.gc.ca/hl-vs/pubs/women-femmes/can-usa/can-back-promo_9-eng.php

169. UBC Centre for Health Services and Policy Research. (2007). *Voices and Choices: Public Engagement in Health Care Policy*. Retrieved on March 8, 2010, from http://www.chspr.ubc.ca/files/publications/2007/chspr07-11.pdf

170. United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved on March 8, 2010, from http://www.un.org/disabilities/convention/conventionfull.shtml

171. Urbanoski, K., Cairney, J., Bassani, D. and Rush, B. (2008). Perceived Unmet Need for Mental Health Care for Canadians with Co-occurring Mental and Substance Use Disorders. *Psychiatric Services March 2008 Vol. 59 No. 3*. Retrieved on March 8, 2010, from http://psychservices.psychiatryonline.org/cgi/reprint/59/3/283

172. Vancouver Costal Health. (2009). *Community Engagement Framework*. Retrieved on March 8, 2010, from http://www.vch.ca/get_involved/community_engagement/

173. Veltman, A., Stewart, D., Tardif, G. and Branigan, M. (2001).health care for People with Physical Disabilities - Access Issues: Discussion. *Medscape General Medicine. 2001; 3(2).* Retrieved on September 29, 2010, from http://www.medscape.com/viewarticle/408122_4

174. Veltman, Albina et al. (2001). Perceptions of Primary health care Services among People with Physical Disabilities. Part 1: Access Issues. *Medscape*

General Medicine. 2001; 3(2). Retrieved on March 8, 2010, from http://www.medscape.com/viewarticle/408122

175. Walker, Sarah. (2009). *Waiting for Care: A Study of Physical and Psychological Symptoms and Health Care Utilization for Pain whilst Waiting for Gynaecological Surgery*. Retrieved on March 8, 2010, from http://qspace.library.queensu.ca/jspui/bitstream/1974/5247/1/Walker_Sarah_200909_MSc.pdf

176. Wiget, M., Turner, D., Tonita, J., King., Nuget, Z., Alvi, R. and Barss, R. (2007). Across-Province Standardization and Comparative Analysis of Time-to-Care Intervals for Cancer. *BMC Cancer 2007, 7:186 doi: 10.1186/1471-2407-7-186*. Retrieved on March 8, 2010, from, http://www.biomedcentral.com/content/pdf/1471-2407-7-186.pdf

177. Wiley InterScience. Web Site. Retrieved on May 15, 2010, from http://www3.interscience.wiley.com/aboutus/

178. Wilson, D., Woodhead-Lyons, S. and Moores, D. (1998). Alberta's Rural Physician Action Plan: An Integrated Approach to Education, Recruitment and Retention. *Canadian Medical Association Journal February 10, 1998; 158(3)*. Retrieved on September 1, 2010, from http://www.cmaj.ca/cgi/reprint/158/3/351

179. Winters, J. (2007). *Medical Instrumentation: Accessibility and Usability Considerations*. Retrieved on March 8, 2010, from http://books.google.com/books?id=y_GtESjOI5IC&dq=Medical+Instrumentation+Accessibility+and+Usability+Considerations&printsec=frontcover&source=bn&hl=en&ei=nQ9OS8qOL4PoM_uFxesM&sa=X&oi=book_result&ct=result&resnum=4&ved=0CBoQ6AEwAw#v=onepage&q=&f=false

180. Wolbring, Gregor. (2005). *The Triangle of Enhancement Medicine, Disabled People, and the Concept of Health: A New Challenge for HTA, Health Research, and Health Policy*. Retrieved on September 28, 2010, from http://www.ihe.ca/documents/HTA-FR23.pdf

181. Woodcock, K. and Pole, J. (2007). Health profile of Deaf Canadians: Analysis of the Canada Community Health Survey. *Can Fam Physician 2007; 53:2140-2141*. Retrieved on March 8, 2010, from http://www.cfp.ca/cgi/reprint/53/12/2140

182. World Health Organization. (2010). *Disabilities*. Retrieved on March 8, 2010, from http://www.who.int/topics/disabilities/en/

183. World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Retrieved on March 8, 2010, from http://www.who.int/classifications/icf/en/

184. World Health Organization. (2003). *Sample of ICF Checklist Version 2.1a, Clinician Form for International Classification of Functioning, Disability and Health.* Retrieved on September 10, 2010, from http://www.who.int/classifications/icf/training/icfchecklist.pdf

185. Wullink, M., Veldhuijzen, W., Schrojenstein Lantman, H., Metsemakers, J., and Dinant, G. (2009). Doctor-Patient Communication with People with Intellectual Disability - a Qualitative Study. *BMC Family Practice 2009, 10:82 doi: 10.1186/1471-2296-10-82*. Retrieved on March 8, 2010, from http://www.biomedcentral.com/content/pdf/1471-2296-10-82.pdf

186. Yukon Health and Social Services. *Web Site*. Retrieved on October 8, 2010, from, http://www.hss.gov.yk.ca/mission.php

187. Yukon Health and Social Services. (2010). *Financial Information: 2010/2011.* Retrieved on March 24, 2011, from, http://www.finance.gov.yk.ca/pdf/budget/2011_12_fininfo_e.pdf

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The Alberta Committee of Citizens with Disabilities is a consumer-directed organization that actively promotes full participation in society for Albertans with disabilities.

Since 1973, ACCD has been Alberta's only provincial, cross-disability organization of and for people living with physical, mental, sensory, learning, or developmental disabilities. We remain a grassroots organization dedicated to improving the quality of life of people with disabilities.

To learn more about ACCD, visit our website at www.accd.net or contact us at 780-488-9088 or 1-800-387-2514.

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